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METHODS FOR IDENTIFYING AIDS CASES IN MEDICARE AND MEDICAID CLAIMS DATA

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A Multi-State Analysis of Persons With AIDS - Summary

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IDENTIFYING AIDS CASES IN CLAIMS DATA FILES

Human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) continue to spread and challenge the health care system. As of June 1996, a total of 529,999 cases of AIDS had been diagnosed in the United States. A large share of the costs of the AIDS epidemic has fallen on the Medicaid and Medicare programs, especially the former. HCFA actuaries have estimated that Medicaid covers approximately 40 percent of all persons with AIDS at some time during their lives, and pays for 25 percent of total AIDS-related costs. Medicare plays a smaller role because fewer people with AIDS qualify on the basis of their age and because, until recently, most people with AIDS did not live long enough to complete the two-year waiting period required of persons who are eligible due to their being disabled.

In 1994, HCFA contracted with Mathematica Policy Research, Inc., (MPR) to develop an AIDS case finding algorithm based on the Centers for Disease Control's (CDC's) 1993 definition of AIDS, to identify Medicare and Medicaid beneficiaries with AIDS. Specifically, the algorithm was applied to two data sets: California Medicaid claims data from 1991 and 1992, and Medicare claims data from 1991 through 1993.

The AIDS case finding methodology attempts to approximate the current CDC surveillance case definition for AIDS in order to identify AIDS cases in claims databases. The case finding algorithm searches the claims databases for diagnosis, procedure, and drug codes that suggest the presence of the elements of the CDC definition. The algorithm then sorts the identified AIDS cases into different groups, depending on the level of evidence available for making the identification. Cases with the strongest evidence are assigned to category one, those with less evidence are assigned to category two, and so on.

Three basic strategies were used to assess the accuracy of the AIDS case finding algorithm. First, earlier efforts to validate case finding methods using diagnostic information in claims records to identify AIDS cases were reviewed. Second, the number of AIDS cases the algorithm identified in the California Medicaid files and national Medicare files was compared with other published estimates of numbers of AIDS cases covered by the two programs. Third, the demographics, care patterns, and mortality rates of the cases identified were examined to assess whether these patterns were consistent with AIDS diagnoses.

California Medicaid Findings: 1991 and 1992

In total, over the two-year period, the algorithm identified 13,012 Medicaid-covered Californians with evidence of AIDS, 8,530 of whom were recorded as being alive at the end of 1992. The CDC estimates that approximately 24,000 of the persons with AIDS reported to the California AIDS case registry were still living at the end of 1992. If one includes the cases in all the evidence level categories, found from applying the case finding algorithm in this study, it is estimated that 36 percent of the people living with AIDS in California at the end of 1992 were covered by Medicaid (8,530/24,000). If only the group for which the most evidence of AIDS is

available (level one), it is estimated that 16 percent of the people living with AIDS in California were covered by Medicaid (3,942/24,000).

In general, a comparison with other sources suggests that the algorithm used in this study identifies somewhat fewer AIDS cases than were actually covered by California Medicaid during the study period. Only if all seven of evidence levels are included, do the numbers estimated come close to those of most other studies, and even then the estimate of 36 percent of cases being covered by Medicaid is lower than most other available estimates.

Medicare Findings: 1991 through 1993

For the three year period, 40,170 Medicare beneficiaries were identified as having evidence of AIDS. At the end of 1993, 41 percent of all cases identified during the three-year period were known to have died. The CDC reported in 1995 that there were 168,115 living AIDS cases in the United States at the end of 1993. The case finding algorithm found between 10,565 (highest evidence level) and 22,927 (all evidence levels) Medicare beneficiaries living with AIDS at the end of the study period. This implies that between 6 and 14 percent of living AIDS cases were covered by medicare at the end of 1993.

To assess the accuracy of the case finding algorithm, this estimate of the percentage of AIDS cases covered by Medicare was compared with other estimates of the percentage of AIDS cases covered by Medicare. All are lower than the high end of the range (14 percent). These differences, however, may be attributable largely to differences in the time period studied. None of the other published estimates focuses on data later than 1991, while this study examined Medicare claims records for 1991 through 1993. Recent developments in AIDS treatment mean that people with AIDS are living longer than in the 1980s. Thus, the number of persons with AIDS who might qualify for Medicare (having survived 29 months following their diagnosis) has presumably increased as well. This comparison leads to the conclusion that the algorithm identified about as many AIDS cases in Medicare claims data as would have expected for the three-year period 1991 to 1993.

I. IDENTIFYING AIDS CASES IN CLAIMS DATA FILES

Human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) continue to spread and challenge the health care system. As of June 1996, a total of 529,999 cases of AIDS had been diagnosed in the United States (Centers for Disease Control and Prevention 1996). A large share of the costs of the AIDS epidemic has fallen on the Medicaid and Medicare programs, which are managed by the Health Care Financing Administration (HCFA). Medicaid is the largest funder for AIDS-related care. HCFA actuaries have estimated that Medicaid covers approximately 40 percent of all persons with AIDS at some time during their lives and pays for 25 percent of total AIDS-related costs (Winkenwerder et al. 1989; and Green and Arno 1990). Medicare plays a smaller role, because fewer people with AIDS qualify on the basis of their age and because, until recently, most people with AIDS did not live long enough to complete the two-year waiting period required of persons who are eligible because of disability (*Medicine and Health* 1993).

In 1994, HCFA contracted with Mathematica Policy Research, Inc., (MPR) to develop an AIDS casefinding algorithm based on the Centers for Disease Control's (CDC's) 1993 definition of AIDS and to use that algorithm to examine the health care utilization and expenditure patterns of persons with AIDS who participate in the Medicare or Medicaid programs. This paper describes the casefinding methodology that MPR developed, presents some initial findings from the application of the casefinding algorithm to Medicaid and Medicare data, and discusses the conclusions than can be drawn regarding the feasibility of identifying AIDS cases using data in the Medicaid and Medicare claims and enrollment files.

This first section describes in detail the process we used to identify AIDS cases in the claims files. We begin with an overview of the casefinding process and then examine the CDC's classification system for HIV infection and AIDS. We then describe the basic elements of the casefinding strategy. From this foundation, we turn to the specific casefinding procedures we have used for the analyses presented in this

report. Finally, we describe how we modified our basic casefinding approach to identify possible AIDS cases in the Medicare and Medicaid data. The next section then describes the accuracy of the casefinding algorithm. It begins with a review of the validation efforts used to establish the validity of prior AIDS casefinding algorithms. It then tests the algorithm with two data sets: California Medicaid claims data from 1991 and 1992 and Medicare data from 1991 through 1993. For each of these data sets, we compare the number of cases identified by the algorithm with independently-derived estimates of the number of California Medicaid recipients with AIDS and the number of Medicare beneficiaries with AIDS.

A. OVERVIEW

The AIDS casefinding methodology attempts to approximate the current CDC surveillance case definition for AIDS (Centers for Disease Control and Prevention 1992) so that it can be useful to identify AIDS cases in claims databases. To establish a diagnosis of AIDS, the CDC requires (1) evidence of HIV infection and (2) either an AIDS-indicator condition or a CD4+ T-lymphocyte (CD4+ T-cell) count below 200 cells/μL. The casefinding algorithm searches the claims databases for diagnosis, procedure, and drug codes that suggest the presence of these elements of the CDC definition. This casefinding method builds on an earlier approach developed by Keyes et al. (1991) and extended by Barbara Turner and the New York State Medicaid staff (Turner et al. 1993a, and 1993b). These earlier approaches were validated using information from California's Medi-Cal AIDS Special Research File and from hospital records in New York (Fanning et al. 1994).

The first step in the casefinding process is to select the claims to be examined. We excluded certain claims (for example, laboratory, X-ray, and equipment claims) because we believe the diagnostic information in these claims is unreliable. The second step is to search the claim files for evidence of HIV infection: diagnosis codes for HIV infection, codes for drugs exclusively used to treat HIV infection, or the diagnosis codes for unspecified immunodeficiency. The third step is to search for evidence of AIDS-indicator conditions and/or conditions that are highly suggestive of a low CD4+ T-cell account. Multiple

claims may be required to establish the presence of certain conditions. The final step is to exclude cases where the immunodeficiency recorded in the claims data is likely to be attributable to a cause other than HIV infection (for example, treatment with immunosuppressants following an organ transplant).[1]

The algorithm sorts the identified AIDS cases into seven groups depending on the level of evidence available for making the identification. The level of evidence depends on two factors:

1. ***Data Comprehensiveness.*** Whether information is available that indicates both (1) evidence of HIV infection, and (2) evidence of an AIDS-indicator condition. Evidence of only HIV infection clearly is insufficient for us to classify the person as having AIDS. However, evidence of some AIDS-indicator conditions is strongly suggestive of AIDS, even in the absence of specific information about HIV infection. We have classified those cases as having AIDS, but have grouped them in our lowest evidence levels.

2. ***Data Accuracy***

   - Whether the information comes from inpatient or outpatient claims. In general, claims filed by inpatient facilities have more accurate diagnostic information than claims from other providers. Consequently, we require two or more outpatient claims (spaced at least one month apart) to establish the presence of a condition, whereas we require only one inpatient claim to establish a condition.

   - Whether the claims contain AIDS-specific codes or codes for HIV infection. We consider the specific ICD-9-CM codes for AIDS to be, in practice, a more reliable indication of HIV infection than of actual AIDS. Therefore, we consider these AIDS-specific codes to be very strong evidence of HIV infection, but somewhat weaker evidence of AIDS.

Eight evidence groups of cases were identified among the adults and adolescents who met the initial selection criteria. Another eight groups were identified among the children initially selected. As Table 1 indicates, most of the rankings for adults and children are based on evidence of (1) an AIDS-indicator defining condition, and (2) evidence of HIV infection. Cases with the most evidence of both were assigned to level 1. Cases with strong evidence of one and less certain evidence of the other were assigned to level

[1]Codes for unspecified immunodeficiency have been used by some providers to record HIV infection in cases where the provider wanted to spare patients from the potential embarrassment (or other consequences) of having an formal HIV diagnosis in their claims record.

TABLE 1

OVERVIEW OF CASEFINDING DECISION RULES

Group	Description
1	Strong evidence of both HIV infection and the presence of an AIDS-indicator condition
2a	Less certain evidence of an AIDS-indicator condition, but strong evidence of HIV infection
2b	Less certain evidence of HIV infection, but strong evidence of an AIDS-indicator condition
3	Less certain evidence of both HIV-infection and the presence of an AIDS-indicator condition
4	No direct evidence of an AIDS-indicator condition, but inpatient code for AIDS strongly suggests a clinical determination of AIDS. Strong evidence of HIV infection
5	No direct evidence of an AIDS-indicator condition, but multiple outpatient codes for AIDS suggest a clinical determination of AIDS. Strong evidence of HIV infection
6	No direct evidence of HIV infection. Multiple occurrences of AIDS-specific illnesses suggest AIDS.
7	No direct evidence of HIV infection. Occurrence of particular AIDS-specific illnesses suggests AIDS.

NOTE: The strength of the evidence depends on the nature and number of claims supporting a diagnosis. Our strongest evidence comes from either (1) an inpatient claim, or (2) two or more outpatient claims that are separated by at least one month. Less certain evidence comes from instances in which we have only a single outpatient claim with a diagnosis or multiple outpatient claims that occur within one month.

AIDS = acquired immunodeficiency syndrome; HIV = human immunodeficiency virus

2a or 2b. Cases with less certain evidence of both were assigned to level 3. Cases with a diagnosis of AIDS (as signified by one of the AIDS-specific ICD-9-CM diagnosis codes for AIDS) but no direct evidence of an AIDS-indicator condition were assigned to level 4 or 5. Cases with no direct evidence of HIV infection but one or more occurrences of selected AIDS-specific conditions were assigned to level 6 or 7.

B. THE 1993 CDC CLASSIFICATION SYSTEM FOR HIV INFECTION AND AIDS

The current classification system for HIV infection and AIDS was specified by the CDC (1992). The system identifies nine groups based on evidence of HIV infection, CD4+ T-lymphocyte (CD4+ T-cell) counts, and specified clinical conditions associated with AIDS. The classification begins with the diagnosis of HIV infection. For persons age 13 or older, there are four accepted indicators of HIV infection:

1. Repeatedly reactive screening tests for HIV antibodies (for example, enzyme immunoassay) with the specific antibody identified by the use of supplemental tests (for example, Western blot, immunofluorescence assay)
2. Direct identification of the HIV virus in host tissues by virus isolation
3. HIV antigen detection
4. A positive result on any other highly specific, licensed test for HIV

After HIV infection has been established, the CDC system classifies people according to their CD4+ T-cell count and the presence of specific conditions. The three CD4+ T-cell categories are:

1. More than 500 cells/μL
2. 200 to 499 cells/μL
3. Fewer than 200 cells/μL

Similarly, the clinical categories reflect increasingly severe conditions associated with HIV infection and AIDS (Table 2). People with more than one condition are classified into the highest category containing one (or more) of their conditions. Thus, group A contains persons with asymptomatic HIV infection who have not previously had a condition listed under category B or category C.

The CDC's AIDS surveillance definition classifies persons as having AIDS if they have evidence of HIV infection and have either (1) at least one of the AIDS-indicator conditions listed under category C, or (2) a CD4+ T-cell count below 200 cells/μL.

The major challenge in using the casefinding algorithm is to distinguish between people with symptomatic HIV infection and people who have AIDS according to the CDC definition. The data available to this study will not permit us to identify persons who meet the CDC definition solely because of a low CD4+ T-cell count. That is, we will be unable to identify persons with asymptomatic AIDS who have a low T-cell count but no other symptoms. The diagnostic information contained in the claims data provide a better basis for distinguishing among people in CDC clinical categories, although it is not always possible to apply the CDC criteria exactly.

C. BASIC BUILDING BLOCKS OF THE CASEFINDING APPROACH

The casefinding approach relies on the diagnosis, service, and demographic data contained in the claims databases to identify possible AIDS cases. In contrast to the analysis of AIDS cases in the California Medicaid program by Keyes et al. (1991), in which claims data were supplemented with death certificate and AIDS case-registry data, our approach relies exclusively on information contained in the claims and enrollment databases.[2]

The basic data used in the casefinding approach are the codes that indicate specific diagnoses associated with each claim. Insurers generally require health care providers to include these codes on

[2]Analyses of AIDS cases in the New York State Medicaid program by Keyes et al. (1991) and Turner et al. (1991a) also relied exclusively on claims and enrollment data.

TABLE 2

CLINICAL CATEGORIES IN THE CDC AIDS/HIV CLASSIFICATION SYSTEM

Category A	Category B	Category C
Asymptomatic HIV infection	Bacillary angiomatosis	Candidiasis of bronchi, trachea, or lungs
Persistent generalized lymphadenopathy	Candidiasis, oropharyngeal (thrush)	Candidiasis, esophageal
Acute HIV infection with accompanying illness or history of acute HIV infection	Candidiasis, vulvovaginal (persistent, frequent, or poorly responsive to therapy)	Cervical cancer, invasive
	Cervical dysplasia (moderate or severe) or cervical carcinoma in situ	Coccidioidomycosis, disseminated or extrapulmonary
	Constitutional symptoms (for example, fever or diarrhea lasting more than one month)	Cryptococcosis, extrapulmonary
	Hairy leukoplakia, oral	Cryptosporidiosis, chronic intestinal
	Herpes zoster involving at least two distinct episodes or more than one dermatome	Cytomegalovirus disease (other than liver, spleen, or nodes)
	Idiopathic thrombocytopenic purpura	Cytomegalovirus retinitis (with loss of vision)
	Listeriosis	Encephalopathy, HIV-related
	Pelvic inflammatory disease (particularly if complicated by tubo-ovarian abscess)	Herpes simplex: chronic ulcers or bronchitis, pneumonitis, or esophagitis
	Peripheral neuropathy	Histoplasmosis, disseminated or extrapulmonary
		Isosporiasis, chronic intestinal
		Kaposi's sarcoma
		Lymphoma, Burkitt's
		Lymphoma, immunoblastic
		Lymphoma, primary, of brain
		Mycobacterium avium complex or *M. kansasii*, disseminated or extrapulmonary
		Mycobacterium tuberculosis, any site
		Mycobacterium, other species
		Pneumocystis carinii pneumonia
		Pneumonia, recurrent
		Progressive multifocal leukoencephalopathy
		Salmonella septicemia, recurrent
		Toxoplasmosis of brain
		Wasting syndrome due to HIV

SOURCE: Centers for Disease Control and Prevention (1992).

AIDS = acquired immunodeficiency syndrome; CDC = Centers for Disease Control and Prevention; HIV = human immunodeficiency virus.

claims in order to explain or justify the service being provided. These data have proved to be a convenient source of information for studying treatment patterns and for obtaining samples of patients with relatively rare conditions. Coding of diagnostic data and the limitations of using claims data for research purposes are discussed in more detail in the following subsections.

The claims data also contain information about services (and, in some cases, prescription drugs) furnished to patients. Depending on the specificity of the treatment, data about services may be used to identify the conditions for which patients are being treated. The final element in case finding is demographic data. Because the incidence of HIV infection, AIDS, and AIDS-indicator conditions varies among demographic groups, these demographic data are useful for distinguishing individuals with HIV infection and AIDS from individuals who have conditions frequently associated with AIDS but who probably do not have AIDS.

1. Coding of Diagnostic Data

Diagnostic information is recorded on claims using the coding system specified in the *International Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM) (U.S. Department of Health and Human Services 1991a). This coding system initially was published in 1979 and is based on the *International Classification of Diseases* published by the World Health Organization. The ICD-9-CM became widely used during the early 1980s. It differed from earlier diagnosis-coding systems by adding a fifth digit to the codes and thereby greatly expanding the specificity of the coding system. All valid ICD-9-CM codes have at least three digits, and some require an additional fourth or fifth digit to classify the condition or disease precisely.

The ICD-9-CM system is constantly changing: new codes are added, existing codes are deleted, the meaning of codes change, and existing codes begin to require further specificity to be valid. For example, the code 279.19 ("other" deficiency of cell-mediated immunity) was used in the early years of the AIDS epidemic to record an AIDS diagnosis. Subsequently, three HIV-related codes were established:

(1) 042.x (HIV infection with specified conditions associated with a poor prognosis), which was intended to indicate AIDS; (2) 043.x (HIV infection with other specified conditions associated with a symptomatic disease), which indicated AIDS-related complex but not AIDS; and (3) 044.x (other HIV infection), which indicated asymptomatic HIV infection. Effective October 1, 1994, these codes were collapsed into a single code, 042 (HIV infection), which includes all clinical manifestations of HIV infection (U.S. Department of Health and Human Services 1994).[3]

2. Limitations of Claims Data

Given the complexity of the coding system and the largely administrative uses for which the diagnostic and service information on claims are collected, using claims data for research purposes is subject to several limitations. The most important limitation is that claims databases contain information only on persons who receive services. Consequently, we are unlikely to identify persons with asymptomatic AIDS for two reasons. First, if they are not obtaining care, they will not have any claims.[4] Second, if they obtain care for conditions unrelated to AIDS, the diagnostic information contained in the claim is unlikely to indicate AIDS status. The magnitude of this problem depends in part on the length of the time period over which we observe individuals' claims histories. The less we observe of an individual's history, the greater the likelihood that claims possibly containing evidence of AIDS will occur outside our time frame and that the individual will not be identified as a possible AIDS case.

Databases maintained by a particular program or insurer have the additional shortcoming of including only claims submitted to the program or plan. For example, only claims covered by Medicare or Medicaid are included in the databases maintained by these programs. This limitation is particularly important with

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[3]A three- or four-digit diagnosis code with an "x" to the right of the last digit denotes the range of codes that begin with those three or four digits. For example, 043.x denotes codes 043.0 through 043.9.

[4]This is a particularly significant problem with the Medicaid population, since poor people are less likely than others to seek care.

respect to the Medicaid data, because it is not unusual for individuals to become temporarily ineligible for Medicaid coverage; any claims incurred during these periods of disenrollment would not be recorded.

Certain kinds of claims are less useful than others for casefinding purposes. In general, claims for outpatient services contain less diagnostic information than do inpatient claims. Inpatient claims typically contain information about the patient's primary diagnosis and several secondary diagnoses. Hospitals using the nationally mandated billing forms for Medicare or Medicaid (form UB82 or UB92) can record as many as 10 diagnoses on a claim.[5] In contrast, outpatient claims generally require only one diagnosis reflecting the primary illness or condition that was treated. The extent to which the diagnostic information contained on inpatient claims surpasses that on outpatient claims varies among databases. For example, this distinction between claim types is evident in Medicare data but not in Medicaid data. In the Medicare database, inpatient claims contain as many as 10 diagnosis fields and have an average of four diagnoses per claim, whereas outpatient claims have only one diagnosis. In the California Medicaid data set (the Tape-to-Tape files), most inpatient claims, like the outpatient claims, carry only the primary diagnosis.

The coding of only a principal diagnosis on some claims may make it difficult to use those claims to identify HIV infection. The principal diagnosis is technically defined as the condition established after study to be chiefly responsible for occasioning the need for care (U.S. Department of Health and Human Services 1991b). Thus, a clinician who treats an HIV-infected person on an outpatient basis for pneumonia may list pneumonia, rather than HIV infection, as the principal diagnosis. Alternatively, a clinician who uses a preprinted list of diagnoses may check HIV infection as the principal diagnosis for an HIV-infected patient, regardless of the particular HIV-related condition for which the patient has sought treatment.

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[5]Claims on the UB82 and UB92 must include an admitting diagnosis and a principal diagnosis. Hospitals may then enter as many as eight other diagnoses for conditions if the conditions coexisted with the principal diagnosis and affected the length of stay. Although the UB82 is mandated for inpatient and outpatient hospital billing under Medicare and Medicaid, not all states use the form.

Other problems with claims-based diagnostic information may arise because of data coding and processing problems. These include the following types of problems:

- Digits may be transposed during the coding process.
- Claims may be submitted with partial coding (for example, conditions coded with three digits when four or five are required). Although the fourth and fifth digits, when applicable, are not optional, many providers routinely omit them or use zeros. This problem is particularly common in systems in which edits check only the first three digits.
- Providers may assign a condition code to a claim for a procedure that tests for that condition, even if the test subsequently indicates that the patient does not have the condition.
- Providers who use a standard group of diagnosis codes (for example, a practice with preprinted billing forms) may use one of the standard codes in lieu of the code for a condition that is not on the standard list.
- Insurers may not require diagnostic information for some types of claims. For example, most state Medicaid programs do not require a diagnosis for Early and Periodic Screening, Diagnosis, and Treatment visits.
- Data consistency checks by the insurer may be insufficient to detect missing or incorrect diagnosis codes.
- Claims data are missing for services covered under some managed care arrangements. An increasing number of individuals are enrolled in managed care plans in which providers are paid on a capitated basis. Claims data are not available for services covered under such managed care arrangements, and encounter data are only rarely available. We therefore eliminated from our study sample all individuals who were flagged in the eligibility files as being enrolled in a capitated managed care plan.

Despite these problems, the diagnostic information on claims has been used to address a wide array of health policy issues. These issues include zidovudine use by men and women with HIV infection (Turner et al. 1994), the effectiveness of therapeutic shoes for Medicare beneficiaries with severe diabetic foot disease (Wooldridge et al. 1993), the use of nonsteroidal anti-inflammatory drugs by elderly people (Griffin et al. 1991), psychotropic drug use and the risk of hip fracture (Ray et al. 1987), and the effect of mandatory case management on the receipt of prenatal care services and birth outcomes (Goldfarb et al. 1991). In addition, several methodological studies have been conducted using claims databases to study

health services issues (Fanning et al. 1994; Mitchell et al. 1994; Lave et al. 1994; Rosenblum et al. 1993; Wysowski and Baum 1993; Fisher et al. 1992; Quam et al. 1993; Whittle et al. 1991; Fisher et al. 1990; and Hornbrook et al. 1985).

3. Specification of Risk Groups

The Medicare and Medicaid enrollment files contain demographic variables, such as age, race, and sex. Previous studies have used these data, combined in some cases with claims data, to delineate risk groups. Keyes et al. (1991) specified six risk groups based on age, sex, and disability status. Turner et al. (1991) specified four risk groups among the adult AIDS population, based on sex, age, and a proxy for drug use. (Because information on drug use is not directly available in the Medicaid data, an algorithm was developed to identify drug users on the basis of codes in the claims data for outpatient and inpatient treatment drug treatment.)

D. IDENTIFYING AND CLASSIFYING AIDS CASES

The casefinding algorithm uses the building blocks in the claims data to identify likely AIDS cases and to sort those cases into groups with decreasing probabilities of meeting the CDC's case- surveillance definition of AIDS. In developing the decision rules for identifying and sorting possible AIDS cases, we made several key assumptions:

- We can be most confident that we have identified an AIDS case when we find evidence of both HIV infection and an AIDS-indicator condition. (This situation conforms to the CDC case definition.)
- ICD-9-CM codes for AIDS (for example, code 042.x) may not distinguish accurately between HIV-infection and AIDS. These codes should be considered strong evidence of HIV infection, but somewhat weaker evidence of AIDS.
- Immunodeficiency codes that are not specific to HIV infection should not be considered evidence of HIV infection if the claims record indicates another possible reason for the immunodeficiency--for example, treatment with immunosuppressants following an organ transplant.

- Inpatient claims contain more accurate diagnostic information than do outpatient claims.
- Diagnostic information on outpatient claims is more convincing when it appears on two or more claims that are at least one month apart.
- Diagnostic information on laboratory, X-ray, and equipment claims is often missing or unreliable. For example, the diagnostic information on laboratory claims may reflect the conditions for which a test is requested rather than an indication of a test's finding. Thus, we ignored diagnostic information from these types of claims.

The following sections describe how AIDS cases were identified and classified on the basis of information contained in the enrollment and claims files.

1. Demographic Groups

Because the incidence of diseases and conditions varies across demographic groups, we varied the decision rules for identifying AIDS cases across certain groups. For example, recurrent pneumonia among young adults can be a good indicator of symptomatic HIV infection, but pneumonia occurs too frequently among an elderly population for its presence to be a good indicator of HIV infection among elderly people. Similarly, the prevalence of HIV-associated diseases in children differs from the prevalence in adults. In addition, evidence of HIV infection in very young children (younger than 18 months) may be misleading, as infants born to HIV-infected mothers may carry in their blood the HIV antibodies of their mothers for up to 18 months, even if the infants are not infected with HIV.

The CDC has specified different criteria for establishing a diagnosis of AIDS in adolescents and adults (ages 13 or older) and children (ages 0 to 12). Because the association between AIDS-indicator conditions and AIDS differs between the elderly population and other adults and between infants and other children, we have specified four age groups:

1. Adolescents and adults ages 13 to 60
2. Adults older than age 60 years
3. Children from birth to 17 months of age

4. Children ages 18 months to 13 years

Previous studies have used information about disability status to specify other risk groups. We chose not to do so because we did not believe it would provide us with reliable evidence of HIV infection or AIDS. Although all persons with AIDS are technically disabled, not all disabled persons with AIDS-indicator conditions have AIDS. For example, individuals with other forms of immunodeficiency may qualify as disabled and also may be vulnerable to opportunistic diseases.

2. Identification of Possible AIDS Cases

To identify cases that are likely to meet the requirements of the CDC's case-surveillance definition, we searched the claims for codes that provide evidence of (1) HIV infection, (2) one of the AIDS-indicator conditions listed under category C of the CDC's case-surveillance definition, or (3) a condition that suggests a CD4+ T-cell count below 200 cells/μL. The review focused on diagnosis codes, supplemented when possible with other codes that may serve as proxies for diagnoses. In our search of the Medicare and Medicaid databases, for example, we examined not only diagnosis codes but diagnosis-related group (DRG) codes and prescription drug codes related to HIV infection and AIDS. In this initial search, cases with any relevant code were flagged as possible AIDS cases. Age specifications and other casefinding requirements were imposed after this initial search.

a. Evidence of HIV infection

Table 3 lists the codes we used as evidence of HIV infection. In the top section of the table are the ICD-9-CM codes providers use to indicate a diagnosis of HIV or AIDS, as well as the 795.8 code that designates a positive finding from a serologic or viral culture test for HIV infection. These codes signify conditions that indicate HIV infection, but not necessarily AIDS or symptomatic infection. The lower two

TABLE 3

CODES USED AS EVIDENCE OF HIV INFECTION

Code	Description
ICD-9-CM Codes	
042.x	AIDS
043.0	AIDS-related complex (ARC)
043.1	AIDS
043.2; 043.3; 043.9	AIDS-related complex (ARC)
044.x	Asymptomatic HIV
279.10; 279.19; 279.3; 279.4; 279.9	Immunodeficiency with predominant T-cell defect; other deficiency of cell-mediated immunity; unspecified immunity deficiency; autoimmune disease, not elsewhere classified; unspecified disorder of immune mechanism
795.8	HIV-positive test
DRG Codes (Medicare)	
488	HIV with extensive operating room procedure
489	HIV with major related condition
490	HIV with or without other related condition
Prescription Drug Codes (Medicaid)	
Selected state-specific drug formulary codes	Zidovudine (Retrovir)[a] Didanosine (Videx)[b] Zalcitabine (HIVID)[c] Stavudine (Zerit)[d] Rifabutin (Mycobutin)[e]

NOTE: Claims for the first four prescription drugs listed are used in the casefinding algorithm as proxies for inpatient HIV claims (044.x). Claims for rifabutin are used as proxies for outpatient HIV claims.

[a]Formerly called azidothymidine or AZT.
[b]Formerly called dideoxyinosine or ddI.
[c]Formerly called dideoxycytidine or ddC.
[d]Formerly called d4T; not approved for use until June 1994.
[e]Not approved for use until December 1992.

AIDS = acquired immunodeficiency syndrome; CDC = Centers for Disease Control and Prevention; HIV = human immunodeficiency virus.

sections of the table contain services codes specific to Medicare and Medicaid that we used as evidence of HIV infection. (The use of these codes is explained in more detail in Section D.)

Table 4 lists the ICD-9-CM codes we used as evidence of AIDS. These codes are a subset of those in Table 3.

Among the codes we used as evidence of HIV infection are several codes in the 279 range, which denote disorders involving the immune mechanism. These disorders may be attributable to causes other than AIDS. These causes include conditions such as collagen diseases, treatment with immunosuppressants following an organ transplant, and dialysis treatment for renal failure. Before the development of specific codes for HIV infection, the 279.xx codes were used to report all disorders of the immune system. In some cases, patients and physicians may still prefer to use these less specific codes, rather than HIV codes, to avoid stigma. To reduce the likelihood of identifying as AIDS cases individuals whose immune system disorders may be attributable to other causes, we eliminated 279.xx codes as evidence of HIV infection in cases where there was evidence of other reasons for the immune system disorder. Appendix Table A.1 lists the ICD-9-CM diagnosis and procedure codes, CPT-4 codes, and DRG codes that we used to identify cases in which immune system disorders were probably due to causes other than AIDS. Cases where the only evidence of HIV infection was a 279.xx diagnosis code were flagged if the case record contained one or more of these "exclusion codes." Flagged cases were treated as having no evidence of HIV infection.[6] Because the coding of inpatient claims tends to be more reliable than the coding of outpatient claims, we required one inpatient claim with a code from Table 4, but two outpatient claims with codes from Table 4, to flag cases with exclusion codes. (The two outpatient claims may occur at any time within the study period.)

[6]As noted in Appendix Table A.1, the only exception to this rule was made in cases of renal failure where there was also evidence of conditions highly specific to AIDS, such as Kaposi's sarcoma.

TABLE 4

CODES USED AS EVIDENCE OF AIDS

Code	Description
042.x	AIDS
043.1	AIDS
279.10; 279.19; 279.3; 279.4; 279.9	Immunodeficiency with predominant T-cell defect; other deficiency of cell-mediated immunity; unspecified immunity deficiency; autoimmune disease, not elsewhere classified; unspecified disorder of immune mechanism

AIDS = acquired immunodeficiency syndrome.

b. Evidence of AIDS-Defining Conditions

In keeping with the distinction drawn by the CDC, we used different diagnosis codes to establish the presence of AIDS-indicator conditions in adolescents and adults (Appendix Tables A.2 and A.3) and in children (Appendix Tables A.4 and A.5). We also required combinations of codes to establish the presence of certain conditions. In some cases, we did so because the CDC definition requires recurrent episodes of the condition. A single episode of pneumonia, for example, would not satisfy the CDC's case requirements. In other cases, we required multiple occurrence of a code, two codes within a set, or a specific combination of codes because the conditions signified by these codes are not by themselves strong indicators of AIDS, or because the condition on the CDC list cannot be represented by a single code. (There is no ICD-9-CM code for wasting syndrome, for example.)

Appendix Table A.2 contains the ICD-9-CM codes used to replicate the CDC's list of AIDS-indicator conditions for adolescents and adults.[7] For most of the conditions, there is a single ICD-9-CM code. However, a number of the conditions required several codes for identification. These "combination-code" conditions are listed in the last two columns of Appendix Table A.2, and the specific rules used to identify these conditions in the claims data are described in Appendix Table A.3. Most of the codes listed in the two tables are for diagnoses related to the conditions in the CDC's category C. However, the list also includes codes for nine conditions that are not on the CDC's list, but that are strongly associated with AIDS and/or a low CD4+ T-cell count.

Appendix Table A.4 contains the ICD-9-CM codes we used to replicate the CDC's list of AIDS-indicator conditions for children younger than age 13. This list includes conditions that are HIV-specific

[7]To be considered evidence of AIDS by our casefinding algorithm, almost all of the codes in these tables must be accompanied by evidence of HIV infection. The only exceptions are codes for conditions that are highly specific to AIDS: cytomegalovirus disease (CMV), Kaposi's sarcoma (KS), *mycobacterium avium* complex or M. kansasii (MAC), *Pneumocystis carinii* pneumonia (PCP), and toxoplasmosis.

among children but not among adults. Appendix Table A.5 explains how combinations of diagnosis codes were used in casefinding among children.

3. Casefinding Decision Rules

The final step in our AIDS casefinding process was to assign the possible AIDS cases identified in our initial search to groups based on the amount of evidence indicating that a person met the CDC's case-surveillance definition of AIDS. Eight groups of cases were identified among the adults and adolescents who met the initial selection criteria. Another eight groups were identified among the children initially selected.

Most of the rankings for adults and children are based on evidence of (1) an AIDS-defining condition, and (2) evidence of HIV infection. Cases with strong evidence of both were assigned to level 1. Cases with strong evidence of one and less certain evidence of the other were assigned to level 2a or 2b. Cases with less certain evidence of both were assigned to level 3. Cases with a diagnosis of AIDS (as signified by one of the ICD-9-CM diagnosis codes for AIDS) but no direct evidence of an AIDS-indicator condition were assigned to level 4 or 5. Cases with no direct evidence of HIV infection but one or more occurrences of AIDS-specific conditions were assigned to level 6 or 7.

The order of the groups reflects our assessment of data quality and comprehensiveness. A key data quality issue is the relative accuracy of the diagnostic information contained on outpatient and inpatient claims. Inpatient claims tend to contain more accurate diagnostic information. In part, this greater accuracy reflects the tendency of hospitals to use trained medical record professionals, rather than billing clerks, to record diagnoses on claims. In addition, with the development of the DRG system, the importance of the diagnostic codes for hospital reimbursements has increased dramatically in recent years. Under the DRG system, Medicare (and some Medicaid programs) reimburse inpatient hospital care on the

basis of specific diagnoses. Thus, it is critical for hospitals to include diagnostic information on their claims.[8]

Given this difference in the reliability of the two claim types, we have assessed the evidence provided by inpatient and outpatient claims differently. In most cases, we consider strong evidence of HIV infection or an AIDS indicator condition to be either (1) an inpatient claim with the diagnosis, or (2) two outpatient claims (spaced at least one month apart, to increase the likelihood that they represent different episodes of illness). A single outpatient claim with a relevant diagnosis is considered less certain evidence. The following subsections describe how the casefinding decision rules were applied to adults and children identified as possible AIDS cases.

b. Application of Decision Rules: Adolescents and Adults

Table 5 shows the specific criteria used to assign adolescents and adults to groups. Evidence level 1 includes the cases that are most likely to meet the CDC's criteria. Individuals older than age 13 are assigned to this group if they have claims showing (1) strong evidence of an AIDS indicator condition, and (2) strong evidence of HIV infection. As noted, strong evidence for an AIDS indicator condition generally is considered to be one inpatient or two outpatient claims with one of the AIDS-defining conditions listed in Appendix Table A.2. In addition, we consider two claims (either inpatient or outpatient) with one of the combinations of codes listed in Appendix Table A.3 to be strong evidence of an AIDS-defining condition. Acceptable evidence of HIV infection for level 1 is one inpatient or two outpatient claims with an HIV-related code from Table 3.[9]

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[8]DRGs do not necessarily improve the clinical accuracy of the diagnostic information, because they give providers an incentive to "code-up," that is, to report a more serious condition in order to receive a larger reimbursement. However, many researchers believe that the diagnostic information on DRG claims is more accurate than that on claims in which reimbursement is not related directly to the diagnosis (such as claims from noninstitutional providers or non-DRG inpatient care).

[9]Codes in the 279.xx range are considered evidence of HIV infection only if there is no evidence of (continued...)

TABLE 5

AIDS CASEFINDING DECISION RULES FOR ADOLESCENTS AND ADULTS

Requirements for Assignment to Specific Evidence Levels		Age Groups[a]	
AIDS-Defining Codes	HIV-Related Codes	13-60 Years	Over 60 Years
Level 1			
One inpatient or two outpatient claims with an AIDS indicator condition (Table A.2), **or** two claims indicating an AIDS indicator condition (Table A.3)[b]	One inpatient or two outpatient claims with an HIV-related code (Table 3)	✓	✓
Level 2a			
One outpatient claim with an AIDS indicator condition (Table A.2)	One inpatient or two outpatient claims with an HIV-related code (Table 3)	✓	✓
Level 2b			
One inpatient or two outpatient claims with an AIDS indicator condition (Table A.2); **or** two claims indicating an AIDS indicator condition (Table A.3)	One outpatient claim with an HIV-related code (Table III.3)	✓	
Level 3			
One outpatient claim with an AIDS indicator condition (Table A.2)	One outpatient claim with an HIV-related code (Table 3)	✓	
Level 4			
One inpatient claim with an AIDS diagnosis code (Table 4)		✓	
Level 5			
Two outpatient claims with an AIDS diagnosis code (Table 4)		✓	
Level 6			
One claim for KS,[c] toxoplasmosis,[d] MAC, PCP, or CMV **and** one claim for a **different** AIDS-indicator condition (Table A.2)	None	✓	
Level 7			
One claim for KS,[c] MAC, or PCP	None	✓	
One claim for toxoplasmosis[d]	None	✓	✓

TABLE 5 *(continued)*

[a]Age is defined as patient age as of the *first* occurrence of a code that contributes to meeting the conditions of AIDS indicator condition presented in Tables A.2 and A.3. If a person never has a condition on those tables, then it is the date of the first claim used to assign the person to a group.

[b]The two (or more) codes/claims necessary to meet any condition on Table A.3 are sufficient to meet this requirement. That is, we do not need two *sets* of claims, each meeting the criteria in Table A.3. Whenever two claims are required, they must be separated by 30 days.

[c]For Groups 5 and 6, only code 176.x is considered evidence of diagnosis of KS (although Table A.2 also allows code 173.x).

[d]Toxoplasmosis codes are accepted as evidence of AIDS only if the person has not had any claims with a code of 771.2 (congenital toxoplasmosis) ever before this claim or within six months after this claim.

AIDS = acquired immunodeficiency syndrome; CMV = cytomegalovirus disease; HIV = human immunodeficiency virus; KS = Kaposi's sarcoma; MAC = *Mycobacterium avium* complex; PCP = *Pneumocystis carinii* pneumonia.

Level 2a relaxes the requirements for evidence of an AIDS-defining condition; only one outpatient claim showing a condition from Appendix Table A.2 is required as evidence of an AIDS-defining condition. Level 2b relaxes the requirements for evidence of HIV infection; only one outpatient claim with an HIV-related code from Table 3 is required to establish HIV infection. Cases that have relatively weak evidence of both an AIDS-defining condition and HIV infection (one outpatient claim for each) are assigned to level 3.

As Table 5 indicates, adults older than age 60 can be assigned only to levels 1, 2a, or 7. The reason for the distinction between age groups is the prevalence of certain AIDS-defining conditions among elderly persons not infected with HIV. In the absence of strong evidence of HIV-infection (one inpatient or two outpatient claims), the presence of an AIDS-defining condition is not a strong indicator of AIDS in an elderly person.[10]

Persons are classified into level 4 only on the basis of an AIDS diagnosis code on an inpatient claim. The fact that we have no evidence of an AIDS-defining condition for these persons gives us less confidence to state that they have AIDS. Nevertheless, the fact that the AIDS code comes from an inpatient claim gives us a reasonable level of confidence in the AIDS diagnosis. Level 5 is similar to level 4, except that the algorithm accepts AIDS codes from two outpatient claims, rather than from one inpatient claim.

Levels 6 and 7 are based on the presence of a claim for Kaposi's sarcoma, toxoplasmosis, *Mycobacterium avium* complex, *Pneumocystis carinii* pneumonia (PCP), or, for group 6, cytomegalovirus disease, as evidence for both HIV infection and the presence of an AIDS-defining diagnosis. These conditions are extremely rare among people younger than age 60 who do not have AIDS. Thus, their presence is strongly suggestive of AIDS. When evidence of Kaposi's sarcoma, toxoplasmosis, *Mycobacterium avium* complex, PCP, or cytomegalovirus disease is accompanied by evidence of another

[10]The exception is toxoplasmosis. Claims with a diagnosis of toxoplasmosis in patients over age 60 are used to group them in level 7.

AIDS-defining condition, the person is classified into level 6. When the only evidence is that of Kaposi's sarcoma, toxoplasmosis, *Mycobacterium avium* complex, or PCP, the person is classified into level 7.

c. Application of Decision Rules: Children

The process for sorting possible childhood AIDS cases is similar to that used for adults, except that the criteria for classification into levels 6 and 7 are more restrictive for children than for adults (Table 6). To be classified in either of these groups, a child must have a diagnosis of PCP or lymphoid interstitial pneumonia (LIP). In addition, the casefinding decision rules for very young children (younger than 18 months of age) reflect the fact that infants born to HIV-infected mothers may carry in their blood the HIV antibodies of their mothers for up to 18 months, even if the infant is not infected with HIV. Hence, children younger than 18 months of age cannot be assigned to level 4 or 5, as these levels require an AIDS diagnosis.

4. Refinements to Earlier Casefinding Methods

The casefinding method used in this study builds on earlier work by Keyes et al. (1991) and Turner et al. (1991b). As indicated throughout this chapter, however, our approach extends the work of these teams by refining their strategies for identifying and classifying possible AIDS cases. Specific enhancements include:

- ***Incorporating the 1993 Changes to the CDC's Case Definition.*** The new algorithm includes the AIDS-indicator conditions that were added to the CDC's 1993 expanded surveillance case definition for AIDS.

- ***Incorporating Recurrent Conditions.*** A number of conditions included in the CDC definition must occur over time in order to indicate AIDS (for example, recurrent pneumonia or wasting syndrome resulting from HIV infection). The algorithm was refined to include a process for checking claims over time so that these conditions could be included in the casefinding process.

- ***Incorporating Conditions for Which There Is No Single ICD-9-CM Code.*** Some of the AIDS-indicator conditions listed by the CDC do not have corresponding ICD-9-CM codes (for example, HIV-related encephalopathy). Other conditions were assigned specific ICD-9-CM codes only recently (for example, esophageal candidiasis was assigned a code in 1992).

TABLE 6

AIDS CASE-FINDING DECISION RULES FOR CHILDREN FROM BIRTH THROUGH AGE 13

Requirements for Assignment to Classification Groups		Age Groups[a]	
AIDS-Defining Codes	HIV-Related Codes	Birth through 17 Months	18 Months to 13 Years
Level 1			
One inpatient or two outpatient claims with a pediatric AIDS-defining condition (Table A.4); **or** two claims indicating a pediatric AIDS-defining condition (Table 5)[b]	One inpatient or two outpatient claims with an HIV-related code (Table III.3)	✓	✓
Level 2a			
One outpatient claim with a pediatric AIDS-defining condition (Table A.4)	One inpatient or two outpatient claims with an HIV-related code (Table 4)	✓	✓
Level 2b			
One inpatient or two outpatient claims with a pediatric AIDS-defining condition (Table A.4); **or** two claims indicating a pediatric AIDS-defining condition (Table A.5)	One outpatient claim with an HIV-related code (Table 3)	✓	✓
Level 3			
One outpatient claim with a pediatric AIDS-defining condition (Table A.4)	One outpatient claim with an HIV-related code (Table 3)	✓	✓
Level 4			
One inpatient claim with an AIDS diagnosis code (Table 4)			✓
Level 5			
Two outpatient claims with an AIDS diagnosis code (Table 4)			✓
Level 6			
One claim for PCP or LIP **and** one claim with a **different** pediatric AIDS-defining condition (Table A.4)	None		✓
Level 7			
One claim for PCP	None	✓	✓

[a] Age is defined as patient age as of the *first* occurrence of a code that contributes to meeting the conditions of AIDS-defining illness (Tables A.4 or A.5). If a person never has a condition on Tables A.4 or A.5, then it is the date of the first claim used to assign the person to a group.

TABLE 6 *(continued)*

[b]The two (or more) codes/claims necessary to meet any condition on Table A.5 are sufficient to meet this requirement. That is, we do not need two *sets* of claims, each meeting the criteria in Table A.5. Whenever two claims are required, they must be separated by 30 days.

AIDS = acquired immunodeficiency syndrome; HIV = human immunodeficiency virus; PCP = *Pneumocystis carinii* pneumonia; LIP = lymphoid interstitial pneumonia.

To capture these conditions in the casefinding process, the algorithm looks for several pieces of information that, when combined, suggest the presence of the AIDS-indicator condition. For esophageal candidiasis, the algorithm looks for one claim for candidiasis of the mouth (112.0) and one claim for esophagitis (530.1).

- ***Incorporating Conditions Often Associated with a Low CD-4+ T-cell Count.*** Claims data do not contain the information needed to implement directly the part of the CDC case definition that pertains to low CD-4+ T-cell counts. However, the claims records do include information about conditions such as bacterial septicemia and microsporidiosis that appear to be very highly correlated with low CD4+ T-cell counts. Therefore, we have included these conditions in our list of AIDS-indicator conditions.

- ***Excluding Claims with Unreliable Diagnostic Information.*** We have excluded laboratory, X-ray, transportation, and equipment claims from the casefinding process. We suspect that the diagnostic information on these claims is unreliable.

- ***Refining the Casefinding Process for Children.*** The algorithm incorporates information about how AIDS and HIV infection affect infants and children in order to improve the casefinding process for children younger than age 13.

- ***Expanding the Set of HIV Indicators.*** In addition to the ICD-9-CM codes that pertain to AIDS and HIV infection, we use selected DRG codes and drug codes as indicators of HIV infection. (Use of these program-specific codes is explained in the following section.)

- ***Excluding Questionable Evidence of HIV Infection.*** ICD-9-CM diagnosis codes in the 279 range may indicate immune system disorders that can be attributed to causes other than HIV infection or AIDS. To improve the probability that we are using these codes as evidence of HIV infection only in cases where there is no other reason for the immune system disorder, we searched the claims data for evidence of other conditions and treatments that may cause immunodeficiencies.

- ***Recognizing Different Levels of Evidence.*** The algorithm groups individuals into seven categories that differ with respect to the evidence for (1) HIV infection, and (2) AIDS-indicator conditions.

- ***Applying the Algorithm to Medicare Data.*** The algorithm can now be applied to data from Medicare claims, as well as data from Medicaid files.

E. CASEFINDING MODIFICATIONS FOR MEDICARE AND MEDICAID DATA

The basic process for identifying possible AIDS cases can be applied to claims data of various kinds, including insurance and hospital discharge data. To identify AIDS cases in the Medicare and Medicaid data, we modified the basic approach to accommodate the special characteristics of these program files.

This section identifies the Medicare and Medicaid claims files used in casefinding and describes the modifications to our basic approach.

1. Files and Claims Used in the Casefinding Process

Claims submitted to Medicare and Medicaid are organized, by claim type, into separate files. The only files excluded from our search were those pertaining to dental services.[11] We included the following files:

- Medicare
  - MEDPAR (includes inpatient and nursing facilities)
  - Outpatient (includes only outpatient hospital)
  - Physician/Supplier: Part B
  - Hospice
  - Home Health
- California Medicaid (Tape-to-Tape)
  - Inpatient
  - Long-Term Care
  - Drug
  - Outpatient (includes all claims not contained on the other three files, except dental)

We did not use all claims in these files in casefinding. In keeping with our assumption that the diagnostic information contained on claims for certain services (laboratory, X-ray, transportation, and equipment) is unreliable, we ignored the diagnostic information on these claims.

2. Screening of Medicare Claims

The casefinding process used to identify possible AIDS cases in the Medicare data involved an additional step that was not necessary for processing the Medicaid data. This step was an initial screening, which was performed to avoid selecting a large number of claims for AIDS-indicator conditions that are relatively common among elderly Medicare beneficiaries (for example, pneumonia). Specifically, we

[11] Dental claims do not include diagnoses.

sought to select claims for persons with some evidence of HIV infection, the AIDS-indicator conditions for levels 6 and 7 or other conditions that are highly correlated with an AIDS diagnosis. After claims with these codes were identified, all other claims incurred by these cases during the study period were pulled.

The screening was performed using a list of ICD-9-CM codes that are suggestive of HIV infection or AIDS (Table 7). The list of conditions was deliberately broad and included most of the conditions in category C in the CDC AIDS/HIV case-classification system (Table 2). The CDC conditions that were excluded from the initial screening list are those that are common enough among the Medicare population that the condition would be a poor screen. For example, the CDC includes wasting syndrome as a AIDS-defining condition; because weight loss has many causes, however, screening a general population on this condition would generate an excessive number of false positives.

This screening list is similar to the one developed by Keyes et al. (1991) and used in their analysis of California and New York State Medicaid data. However, we deleted some codes from that list and added others. In most cases, codes were deleted because experience has shown that using these codes to select cases from the Medicare data identifies a large group of elderly individuals, in whom many of these conditions are relatively common. The following 10.codes or ranges of codes were deleted: (1) 010.2-018.99 (tuberculosis), (2) 054.0-054.9 (herpes simplex), (3) 112.0-112.9 (candidiasis), (4) 114.x (coccidioidomycosis), (5) 173.x (Kaposi's sarcoma and other malignant neoplasms of the skin), (6) 200.0-200.08 (selected lymphomas), (7) 200.20-200.28 (selected lymphomas), (8) 279.8 (other specifieddisorders involving the immune mechanism), (9) 421.x (bacterial endocarditis), and (10) 484.1 (pneumonia in cytomegalic inclusion disease).[12]

We also added four codes or ranges of codes. Two designate conditions that have been found to be strongly associated with AIDS: (1) 321.0 (cryptococcal meningitis), and (2) 528.6 (leukoplakia of oral

[12]Information obtained more recently would lead us to include 484.1 in screens performed in the future.

TABLE 7

ICD-9-CM CODES FOR FIRST-STAGE SCREENING OF MEDICARE CLAIMS FOR POSSIBLE AIDS CASES

Code	Description
003.1	*Salmonella* septicemia
007.2	Cryptosporidiosis
031.8, 031.9	Disseminated atypical mycobacterial infection[a]
042.x-044.x	HIV-related (AIDS, ARC, other)
046.3	Progressive multifocal leukoencephalopathy
078.5	Cytomegalovirus disease[a]
117.5	Cryptococcosis
127.2	Strongyloidiasis
130.0-130.9	Toxoplasmosis
136.3	*Pneumocystis carinii* pneumonia
176.x	Kaposi's sarcoma
279.10	Immunodeficiency with predominant T-cell defect, unspecified
279.19	Deficiency of cell-mediated immunity, other
279.3	Unspecified immunity deficiency
279.4	Autoimmune disease, not elsewhere classified
279.9	Unspecified disorder of immune mechanism
321.0	Cryptococcal meningitis
516.8	Lymphoid interstitial pneumonia
528.6	Leukoplakia of oral mucosa (oral hairy leukoplakia)
795.8	HIV-positive test code

[a] These codes were omitted from our initial screening list. Hence, individuals with *Mycobacterium avium* complex and/or cytomegalovirus disease whose claims records show no evidence of HIV infection or other AIDS indicator conditions were not selected. If they had been selected, such cases would have been assigned to group 6 or 7, depending on whether they were diagnosed with both *Mycobacterium avium* complex and cytomegalovirus disease or with only one of the two diseases.

AIDS = acquired immunodeficiency syndrome; ARC = AIDS-related complex; HIV= human immunodeficiency virus.

mucosa). In addition, we replaced the general code for Kaposi's sarcoma (173.x), which was used to designate not only Kaposi's sarcoma but also various malignant neoplasms of the skin, with a new code that is specific to Kaposi's sarcoma (176.x). (However, the broader code [173.x] was accepted as evidence of Kaposi's sarcoma for assigning individuals to groups based on the probability that they have AIDS.) We also added the code that designates a positive finding from a test for HIV infection (795.8).[13]

b. Service Codes

The Medicare and Medicaid claims data also include service information that can be used to identify possible AIDS cases. For example, inpatient hospital Medicare claims contain codes indicating the DRG to which patients have been assigned for billing. Three DRG codes pertain to the treatment of HIV-related conditions. Because each of these DRGs encompasses diagnoses not included in the CDC's surveillance case definition, we used the three as indicators of HIV infection, rather than as evidence of AIDS (Table 3).

Two types of service codes were used to identify possible AIDS cases in the Medicaid data. Individuals whose claims records indicated the receipt of special services (such as attendant care) under the California Medicaid program's AIDS waiver program were flagged in our initial search, as were individuals with claims for certain HIV-specific drugs.[14] In some cases, a drug claim was treated as equivalent to a claim with a diagnosis of the condition the drug is used to treat. Claims for antiretroviral drugs (such as zidovudine) were treated as evidence of HIV infection.[15] Table 8 lists the drugs used in the

[13]Codes in the 700 range generally pertain to "symptoms, signs, and ill-defined conditions." Providers may use the 795.8 code (for an HIV-positive test) rather than the 044 code (for HIV infection) because they performed the test but conducted no follow-up with the patient to confirm the diagnosis.

[14] Examination of the claims filed for persons who received AIDS waiver services revealed that each of these individuals had at least one claim with an HIV or AIDS diagnosis code. We therefore relied on the HIV or AIDS codes to establish HIV infection or AIDS, rather than using receipt of AIDS waiver services as a proxy for an HIV or AIDS diagnosis.

[15]Claims for Rifabutin, which is used to treat atypical microbacterial infection in HIV-infected persons, were also treated as evidence of HIV infection.

TABLE 8

PRESCRIPTION DRUG CLAIMS USED AS PROXIES FOR AIDS-RELATED DIAGNOSES

	AIDS-Related Diagnoses		
Drug	Proxy Diagnosis Code	Description	Claim Type
Zidovudine (Retrovir)[a] Didanosine (Videx)[b] Zalcitabine (HIVID)[c] Stavudine (Zerit)[d] Rifabutin (Mycobutin)[e]	044.x	Asymptomatic HIV	Inpatient Outpatient
Ganciclovir sodium (Cytovene) Foscarnet sodium (Foscavir)[f]	078.5	Cytomegalovirus	Outpatient
Interferon alfa-2a (Alpha-2a), recombinant (Roferon-A)	173.x[g]	Kaposi's sarcoma (includes Kaposi's sarcoma and other malignant neoplasms of the skin)	Outpatient

NOTE: HIV = human immunodeficiency virus.

[a]Formerly called azidothymidine or AZT.

[b]Formerly called dideoxyinosine or ddI.

[c]Formerly called dideoxycytidine or ddC.

[d]Formerly called d4T; not approved for use until June 1994.

[e]Not approved for use until December 1992.

[f]Also used for treatment of herpes.

[g]Claims for these drugs are treated as equivalent to a specific diagnosis of Kaposi's sarcoma (176.x) if there is another outpatient claim in the case record with a 176.x diagnosis code.

casefinding algorithm, along with the HIV-related condition for which each drug is prescribed. In most cases, the drug claim was used as a proxy for an outpatient claim for a condition or HIV infection. However, in cases in which use of the drug is strongly associated with HIV infection, we treated the drug claim as a proxy for an inpatient claim. The subset of drugs used as evidence of HIV infection are also listed in Table 3.

II. ACCURACY OF THE CASEFINDING ALGORITHM

We used three basic strategies to assess the accuracy of our AIDS casefinding algorithm. First, we examined earlier efforts to validate casefinding methods that, like our own, use diagnostic information in claims records to identify AIDS cases. Second, we compared the number of AIDS cases the algorithm identified in the California Medicaid files and national Medicare files with other published estimates of numbers of AIDS cases covered by the two programs. Third, we examined the demographics, care patterns, and mortality rates of the cases we identified to assess whether these patterns were consistent with AIDS diagnoses. The latter analysis is described in Fasciano, et al. (1997). In this section, we briefly discuss the first two validation efforts and then present some basic conclusions about the accuracy of our approach.

A. EARLIER VALIDATION EFFORTS

The teams of researchers who developed the earlier casefinding methodology on which our approach is based assessed the accuracy of their casefinding methods using information from external databases. Their results suggest that our version of the algorithm, which we believe significantly improves on these earlier casefinding efforts, provides a good screen for identifying AIDS cases in the claims data.

Keyes et al. (1991) verified the AIDS status of cases selected by their casefinding algorithm using the Medi-Cal AIDS Special Research File, which the State of California created by matching Medicaid claims files to the state's AIDS registry. The results suggest that their algorithm was highly specific but somewhat less sensitive than one would like. Of the 976 verified AIDS cases on the Medi-Cal AIDS Special Research File, Keyes et al. found that 93 percent had been identified by their casefinding algorithm. Of the 1,152 Medicaid recipients that they algorithm identified as being AIDS cases, 78 percent were known to the state's AIDS registry.

Lacking access to AIDS case registry data, Fanning et al. (1994) asked two hospitals that treated AIDS patients to determine if the AIDS cases known to the hospital had been identified by their casefinding algorithm. Of the 125 Medicaid-eligible patients treated in AIDS clinics at the two hospitals, all but one was found to have been identified in the Medicaid data by the casefinding algorithm. While this is a small sample, it suggests that the algorithm developed by Fanning et al. was sensitive in identifying known AIDS cases.

B. AGGREGATE ESTIMATES OF AIDS CASES IN MEDICAID AND MEDICARE

We also assessed the accuracy of our algorithm by comparing the number of AIDS cases we identified with the number of cases reported in other published sources. Our results are based on the application of the casefinding algorithm to two data sets:

1. Medicaid data from California for calendar years 1991 and 1992
2. Medicare data from the United States for calendar years 1991 through 1993

1. California Medicaid Findings: 1991 and 1992

In this section, we present the number of Medicaid recipients our casefinding algorithm identified as AIDS cases in the California Medicaid claims data for 1991 and 1992. We then compare that number with other estimates of Medicaid-covered AIDS cases in California.

a. Number of AIDS Cases Identified by the Casefinding Algorithm

Table 9 shows the number of individuals identified in California Medicaid data who met the requirements for each AIDS evidence level during the two-year period from 1991 through 1992. This table presents unduplicated counts of the number of individuals in each evidence level; individuals are assigned to the highest level for which they qualified. In total, over the two-year period, the algorithm

TABLE 9

ALGORITHM-IDENTIFIED AIDS CASES: CALIFORNIA MEDICAID, 1991 AND 1992

	Evidence Level								
	1	2a	2b	3	4	5	6	7	All Levels
Total Number of Individuals	6,944	978	356	169	1,103	2,873	175	414	13,012
Percentage of Total Individuals Identified	53.4	7.5	2.7	1.3	8.5	22.1	1.3	3.2	100.0
Total Number of Individuals Known to Have Died in Study Period	3,002	310	110	50	461	433	44	72	4,482
Percentage of Identified Individuals Known to Have Died in Study Period	43.2	31.7	30.1	29.6	41.8	15.1	25.1	17.4	34.4
Number of Individuals Thought to Be Alive at End of Study Period	3,942	668	246	119	642	2,440	131	342	8,530

AIDS = acquired immunodeficiency syndrome.

identified 13,012 Medicaid-covered Californians who have evidence of AIDS. Of these, more than half (53 percent) are in level 1, the group for which we have the most evidence of AIDS. The group with the next greatest number of persons is level 5 (individuals who have outpatient claims with an AIDS diagnosis but whose claims do not include any evidence of an AIDS indicator condition), with 22 percent of cases. Table 9 also shows that many of the people identified by the casefinding algorithm died during the two years for which we have data.[16] The highest rates of death occurred among the individuals classified in levels 1 and 4. More than 40 percent of the people in each of those evidence levels died during 1991 and 1992. Just under one-third of people in levels 2a, 2b, and 3 died during that two-year period.

If we include cases at all evidence levels (levels 1-7), the casefinding algorithm identified 13,102 AIDS cases, 8,530 of whom were recorded as being alive at the end of 1992. If we include only those cases with the most evidence of AIDS (level 1), we identified 6,944 AIDS cases, 3,942 of whom were thought to be alive at the end of 1992.

The CDC estimates that approximately 24,000 of the persons with AIDS reported to the California AIDS case registry were still living at the end of 1992.[17] If we aggregate all evidence levels from the algorithm, we would estimate that 36 percent of the people living with AIDS in California at the end of 1992 were covered by Medicaid (8,530/24,000). If we use only the group for which we have the most evidence of AIDS, we would estimate that 16 percent of the people living with AIDS in California were covered by Medicaid (3,942/24000).

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[16]We have estimated the number of deaths using information from the Medicaid eligibility files. These files often fail to record some deaths, so our estimates are likely to underestimate the actual number of deaths among the people identified by the algorithm.

[17]Personal communication from Dr. Richard Selik, Centers for Disease Control, 1996.

b. Independent Estimates of the Percentage of AIDS Cases Covered by Medicaid

To assess the accuracy of the casefinding algorithm, we compared our algorithm-based estimates of the proportion of California AIDS cases with Medicaid with other estimates of the proportion of AIDS cases covered by Medicaid. In general, this comparison with other studies suggests that the algorithm identifies somewhat fewer AIDS cases than were actually covered by California Medicaid during the study period. Only if we include as AIDS cases individuals in all seven of our evidence levels, do we approach the numbers estimated by most other studies, and even then our estimate of 36 percent of cases being covered by Medicaid is lower than most other available estimates.

The process of comparing our estimates with other estimates was complicated by the substantial variation in the published estimates. This variation reflects differences in the time period studied, the data sources used, and the methods by which AIDS cases were identified. We reviewed estimates based on surveys, AIDS registry data combined with survey data, Medicaid claims data, and hospital discharge data.

Survey data generally suggest that about half of all AIDS cases are covered by Medicaid. The most comprehensive currently-available national survey data about people with HIV-related disease come from the AIDS Costs and Service Utilization Survey (ACSUS). This is a longitudinal study of persons with HIV-related disease receiving care at major providers of medical services in 10 cities. One analysis of ACSUS data found that 53 percent of the 1,900 adults and 140 children with HIV infection reported some type of public health coverage (Schur and Berk 1994).[18] Among this population, people with AIDS had the highest rates of public insurance coverage (62 percent), compared with patients with symptomatic HIV (50 percent) and patients with asymptomatic HIV infection (37 percent).

While these estimates suggest that the fraction of AIDS cases covered by Medicaid is much larger than our algorithm would indicate (62 percent rather than our 36 percent), the two sets of estimates are not

[18]Another analysis of ACSUS data (Fleishman et al. 1994), which looked at a different subpopulation (HIV-infected adults), found the proportion covered by some type of public insurance to be 43.2 percent.

strictly comparable. First, the ACSUS estimates include all public coverage (primarily Medicaid, Medicare, and Veterans' Programs) rather than just Medicaid. Also, the ACSUS numbers are from a national sample, not just California. There is also sampling error in the survey estimates (because the ACSUS sample is not a strict probability sample estimates based on it cannot be generalized with a known level of confidence to the national or California AIDS population). Nevertheless, the ACSUS data suggest that our algorithm, when applied to two years of Medicaid data, may miss a substantial number AIDS cases.

A similar conclusion emerges when our algorithm-based estimates of the proportion of AIDS cases covered by Medicaid are compared with estimates based on surveys of people included in AIDS registries. A multistate AIDS surveillance project, which surveyed 1,958 adults with AIDS reported to the CDC between mid-1990 and mid-1992, found that 49.5 percent had Medicaid coverage (Diaz et al., 1994). This figure is consistent with an analysis of Medi-Cal data by Hiehle et al. (1990), which estimated that the fraction of California AIDS cases covered by Medicaid was 43 percent in 1987, up from 29 percent in 1982.

Hospital discharge data provide another perspective on our estimates. Estimates of the fraction of HIV-related hospitalizations covered by Medicaid nationwide or in selected areas of the country from 1986 to 1990 range from 28 to 55 percent.[19] Although these estimates are not directly comparable to our own, differing in the unit of analysis (covered hospitalizations versus covered individuals) and case selection criteria (evidence of HIV-related disease versus evidence of AIDS), estimates based on hospital discharge

[19]Whether the percentage of AIDS hospitalizations covered by Medicaid is a reasonable approximation of the overall fraction of the AIDS population with Medicaid depends on whether persons with AIDS covered by Medicaid are hospitalized at the same rate as are other persons with AIDS. Analyses of correlates of care indicate that hospitalization rates for publicly insured persons with AIDS do not differ significantly from hospitalization rates for privately insured persons with AIDS (Fleishman et al. 1994; and Fleishman and Mor 1993). (These analyses did not specifically examine the effects of Medicaid coverage, but Medicaid is known to be the largest provider of public insurance for people with AIDS.)

data shed light on time trends and regional variations in the proportion of AIDS cases covered by Medicaid.[20]

One of the highest estimates of the proportion of hospitalizations covered by Medicaid comes from an analysis of U.S. Hospital AIDS Survey data from 1987, which collected data from 623 acute care hospitals nationwide (Andrulis et al. 1989). Responding hospitals reported that Medicaid was the primary payer for 44 percent of AIDS-related admissions nationwide and for 55 percent of AIDS-related admissions in the West. An analysis of data from the Hospital Cost and Utilization Project (HCUP-2), which includes comprehensive data from a national sample of 500 U.S. hospitals for approximately the same period (1986 and 1987) found Medicaid to be the expected payer for a somewhat lower proportion, 36.9 percent, of HIV-related discharges nationwide (Harris and Ball 1995).

Other analyses of hospital discharge data indicate a substantial increase in the proportion of Medicaid-covered discharges over the latter half of the 1980s. An analysis of data from the National Hospital Discharge Survey (NHDS), a nationally representative probability survey of discharges from nonfederal hospitals, found that the proportion of discharges for which Medicaid was expected to be the primary payer rose from 27.4 percent to 40.1 percent between 1985 and 1990 (Kozak et al. 1993). Assuming this trend continued, we would expect to find an even higher percentage of discharges covered by Medicaid during our study period (1991 to 1992).

The literature also shows that the fraction of AIDS cases covered by Medicaid varies across regions. For example, an analysis of 1988 hospital discharge data from New York and of 1987 hospital discharge data from Los Angeles and San Francisco found that the percentage of HIV-related discharges for which

[20] Most hospital discharge studies use a conservative screen to identify HIV-related discharges. Harris and Ball (1995) selected cases with ICD-9-CM codes 042, 043, 044, or 795.8, indicating HIV infection. Kozak et al. (1993) selected cases with codes 042, 043, 044, 279.19, or 795.8, indicating HIV infection. Green and Arno (1990) selected cases with codes 042, 043, 044, indicating HIV infection, or 136.3, indicating PCP.

Medicaid was expected to be the primary payer in the three cities was 54.6, 27.8, and 30.0, respectively (Green and Arno 1990).

Overall, the comparisons to the full range of alternative estimates suggests that our algorithm under-identifies AIDS cases when applied to Medicaid data from a two year period. The evidence suggests that even when all evidence levels are considered together, the algorithm should have identified as much as 30 percent more cases in order to match the estimates of Medicaid-covered AIDS cases suggested by surveys of people listed in AIDS registries.[21] At the same time, it appears that the cases the algorithm does identify do have AIDS. More than half the cases identified by the algorithm have claims showing both evidence of HIV infection and evidence of an AIDS-indicator condition. Furthermore, the high death rates among the cases identified by the algorithm, even those for which we have relatively little evidence of AIDS, reflect the severity of illness among the identified cases. Thus, it appears that the algorithm can provide a basis for identifying a large subset of all AIDS cases when it is applied to Medicaid claims data from a two-year period.

2. Medicare Findings: 1991 Through 1993

In this section, we present the number of AIDS cases identified in the national Medicare claims data for 1991 through 1993. We then compare that number with other estimates of Medicare-covered AIDS cases.

a. Number of AIDS Cases Identified by the Casefinding Algorithm

Table 10 shows unduplicated counts of individuals we identified in national Medicare data who met the requirements for each evidence level during the three-year period from 1991 through 1993. For the

[21] An 30 percent increase would raise our estimate (based on all evidence levels) from 36 percent to 47 percent. That figure would lie in the middle of the range noted by Diaz et al. (1994) and Hiehle et al. (1990).

TABLE 10

ALGORITHM-IDENTIFIED AIDS CASES: MEDICARE, 1991-1993

	Evidence Certainty Level								All Levels
	1	2a	2b	3	4	5	6	7	
Total Number of Individuals	24,494	2,821	1,627	626	2,661	5,359	753	1,829	40,170
Percentage of Total Individuals Identified	61.0	7.0	4.1	1.6	6.6	13.3	1.9	4.6	100
Total Number of Individuals Known to Have Died in Study Period	13,929	788	379	200	910	496	255	286	17,243
Percentage of Identified Individuals Known to Have Died in Study Period	56.9	27.9	23.3	31.9	34.2	9.3	33.9	15.6	40.6
Number of Individuals Thought to Be Alive at End of Study Period	10,565	2,033	1,248	426	1,751	4,863	498	1,543	22,927

AIDS = acquired immunodeficiency syndrome.

three-year period, we identified 40,170 Medicare-covered individuals who have evidence of AIDS. Of these, 61 percent are in level 1, the group with the most evidence of AIDS. The group with the next greatest number of individuals is level 5 (individuals who have outpatient claims with an AIDS diagnosis but whose claims do not include any evidence of an AIDS-indicator condition), with 13 percent of cases. Table 10 also shows the number of individuals, by the highest level assigned, who are known to have died during the study period. (Deaths were estimated using data in the Medicare eligibility files.) Almost 57 percent of individuals in level 1 died during the three-year study period. Levels 3, 4, and 6 also showed high death rates (32 to 34 percent). By the end of 1993, 41 percent of all cases identified during the three-year period were known to have died.

If we include cases at all evidence levels, we identified 40,170 AIDS cases, 22,927 of whom were thought to be alive at the end of the study period. If we include only those cases with the most evidence of AIDS (level 1), we identified 24,494 AIDS cases, 10,565 of whom were thought to be alive at the end of the study period.

The CDC reported in 1995 that there were 168,115 living AIDS cases in the United States at the end of 1993 (Centers for Disease Control and Prevention 1995). As noted, our casefinding algorithm found between 10,565 and 22,927 Medicare beneficiaries living with AIDS at the end of the study period depending on the evidence levels included. By our estimate, then, between 6 and 14 percent of the living AIDS cases in the United States were covered by Medicare at the end of 1993.

b. Percentages of U.S. AIDS Cases Estimated to Be Covered by Medicare

To assess the accuracy of the casefinding algorithm, we compared our estimate of the percentage of AIDS cases covered by Medicare with other estimates of the percentage of AIDS cases covered by Medicare. As with Medicaid, the estimates vary widely.[22] All are lower than the high end of our range

[22]To provide another perspective on our estimates, we used data from the CDC's AIDS Public (continued...)

(14 percent). These differences, however, may be attributable largely to differences in the time period studied. None of the published estimates focuses on data later than 1991, while we examined Medicare claims records for 1991 through 1993. Recent developments in AIDS treatment mean that people with AIDS are living longer than in the 1980s. Thus, the number of persons with AIDS who might qualify for Medicare (having survived 29 months following their diagnosis) has presumably increased as well.

The lower end of our range (six percent) is between the two available survey-based estimates of the fraction of persons with AIDS nationwide who have Medicare coverage. For example, data from the ACSUS suggest that, in spring 1991, between 8.4 percent and 12 percent of persons with AIDS (identified through medical records) had Medicare coverage.[23] This survey includes more than 1,900 adults and adolescents infected with HIV who were identified in clinics located in 10 cities (Berk et al. 1993). By contrast, the Multistate AIDS Surveillance Project, which surveyed 1,958 adults with AIDS reported to the CDC between mid-1990 and mid-1992, found only 2.2 percent of AIDS cases to be covered by Medicare.

Our estimates of the number of people with AIDS who have Medicare are higher than previous estimates based on hospital discharge data. Estimates of the fraction of HIV-related hospitalizations that were covered by Medicare range from two percent to about six percent.[24] The lower figure was reported

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[22](...continued)
Information Data Set to identify persons living with AIDS who, by the end of 1993 (1) might have turned age 65, or (2) had survived at least 29 months after diagnosis and hence might have been eligible for Medicare as aged or disabled (assuming these individuals are adults with sufficient work history to qualify for social security benefits). We identified 1,563 individuals in the first group, 44,329 in the second, and 704 who met both conditions. By this count, as many as 46,596 persons living with AIDS were potentially eligible for Medicare at the end of 1993. This number constitutes 27.7 percent of all persons living with AIDS at the time. Our estimates are well below this estimated maximum proportion of AIDS cases possibly covered by Medicare.

[23]Fleishman, unpublished tabulations from the ACSUS data, personal communication, January 19, 1996.

[24]The percentage of AIDS hospitalizations covered by Medicare could be used to estimate the overall (continued...)

in an analysis of the 1987 U.S. Hospital AIDS Survey (Andrulis et al. 1989). Responding hospitals reported that Medicare was the primary payer for two percent of HIV-related admissions. An analysis of 1988 hospital discharge data from New York and of 1987 hospital discharge data from Los Angeles and San Francisco found that the percentage of discharges for which Medicare was expected to be the primary payer in the three cities ranged from 2.7 to 4.7 percent (Green and Arno 1990). Similarly, Harris and Ball (1995) found Medicare to be the primary payer for 3.6 percent of HIV-related admissions in the sample of hospitals participating in the 1986 and 1987 HCUP surveys. An analysis by Ball and Turner (1991) of HCUP data from 1986-87 found the proportion of HIV-related hospitalizations covered by Medicare to be considerably higher in some areas. Of suspected AIDS discharges reported by the sample of hospitals in the HCUP study, the percentage of discharges for which Medicare was expected to be the primary payer ranged from 2.2 percent in New York State to 9.8 percent in the North Central region. The weighted average of Medicare discharges reported (where the weights are proportional to the number of discharges in the area) was slightly less than six percent. Again, it is reasonable to expect that the fraction of HIV-related discharges would have been higher three to five years later, during our study period.

This comparison leads us to conclude that the algorithm identified about as many AIDS cases in Medicare claims data as we would have expected for the three-year period 1991 to 1993.

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[24](...continued)
fraction of the AIDS population with Medicare if people with AIDS covered by Medicare are hospitalized at the same rate as other persons with AIDS. However, hospitalization rates for the two groups probably differ. Because persons with AIDS generally do not qualify for Medicare until 29 months after diagnosis, those with Medicare coverage are, on average, at a later stage of disease than are other persons with AIDS and may consequently be hospitalized at a higher rate. If so, the percentage of AIDS hospitalizations is an upwardly biased estimate of the percentage of persons with AIDS covered by Medicare.

III. CONCLUSIONS

One key conclusion we can draw from this initial application of the algorithm is that it is feasible to operationalize much of the CDC AIDS case surveillance definition to identify AIDS cases in the Medicare and Medicaid claims data. The claims files do not provide all of the data needed to identify persons who meet the CDC AIDS case surveillance definition (for example, claims data do not allow us to identify HIV-infected persons who meet the CDC AIDS case definition solely because of a low CD4+ T-cell count). However, the diagnosis, service, and demographic data in the claims and enrollment files are sufficient to permit the identification of a group of cases whose morbidity and mortality rates strongly suggest AIDS. The aggregate number of AIDS cases identified by the algorithm is consistent with the number of AIDS cases that would be expected based on other available data when the algorithm is applied to three years of Medicare claims data. It seems to under-identify AIDS cases when applied to two-years of Medicaid claims data.

Our general impression from analysis of the data is that the algorithm is probably highly specific but less sensitive than one would like, even when we include as AIDS cases individuals in all evidence levels (1 through 7). The sensitivity of the algorithm appears to be a greater issue for analyses of Medicaid data than for analyses of Medicare data, as the Medicaid files contain less diagnostic information that can be used to identify possible AIDS cases than do the Medicare files. For example, the Medicaid hospital claims records generally contained only one diagnosis code while the Medicare hospital claims often had five or more diagnosis codes. Moreover, the Medicaid claims histories we searched for evidence of AIDS were limited to two years of data, while the Medicare claims histories could be up to three years long. Comparisons with other published statistics support our conclusion that the algorithm may have identified a higher proportion of AIDS cases in the Medicare data set than in the California Medicaid data set. These

comparisons also suggest that to identify appropriate aggregate numbers of AIDS cases in the claims data, we must include cases in all evidence levels.

Given these results, we conclude that the algorithm provides a viable and useful tool for analyzing the health care utilization of persons with AIDS who are covered by large insurance programs. It appears that the cases identified are likely to have AIDS and so analyses of the care patterns of algorithm-identified AIDS cases can provide a means to understand what is happening to this population. It can also provide a means to estimate the costs of AIDS care that are borne by Medicare and Medicaid. It is much cheaper than a survey for generating information about enrollment, service use, and expenditure profiles and can cover a wider geographic area than AIDS registries. However, the algorithm does have important limitations. It appears to work better when applied to longer periods of data and to claims files that contain more diagnostic information. Also, analyses of algorithm-identified Medicaid cases are apt to underestimate the aggregate cost of AIDS to the program because the algorithm under-identifies AIDS cases (at least when applied to two years of data). Finally, the algorithm will not provide the detail of a survey or have the accuracy of an AIDS registry. Thus, it represent one of several methods administrators and researchers can use to study this important population.

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APPENDIX

SUPPLEMENTAL TABLES

TABLE A.1

DIAGNOSIS AND PROCEDURE CODES USED TO ELIMINATE 279.XX DIAGNOSIS CODES AS EVIDENCE OF HIV INFECTION

Condition	Type of Code	Code
Rheumatic Disorders		
Rheumatoid arthritis	ICD-9-CM Diagnosis Code	714.x
Psoriatic arthritis	ICD-9-CM Diagnosis Code	696.0
Ankylosing spondylitis	ICD-9-CM Diagnosis Code	720.0
Collagen Diseases		
Polyarteritis nodosa	ICD-9-CM Diagnosis Code	446.0
Wegener's granulomatosis	ICD-9-CM Diagnosis Code	446.4
Giant cell arteritis	ICD-9-CM Diagnosis Code	446.5
Arteritis, unspecified	ICD-9-CM Diagnosis Code	447.6
Systemic lupus erythematosus	ICD-9-CM Diagnosis Code	710.0
Systemic sclerosis	ICD-9-CM Diagnosis Code	710.1
Dermatomyositis	ICD-9-CM Diagnosis Code	710.3
Polymyositis	ICD-9-CM Diagnosis Code	710.4
Unspecified diffuse connective tissue disease	ICD-9-CM Diagnosis Code	710.9
Dermatologic Diseases		
Mycosis fungoides	ICD-9-CM Diagnosis Code	202.1
Pemphigus	ICD-9-CM Diagnosis Code	694.4
Ophthalmic Diseases		
Optic neuritis	ICD-9-CM Diagnosis Code	377.3x
GI Diseases		
Ulcerative colitis	ICD-9-CM Diagnosis Code	556
Regional enteritis	ICD-9-CM Diagnosis Code	555.0-555.9
Respiratory Diseases		
Sarcoidosis	ICD-9-CM Diagnosis Code	135
Pulmonary eosinophilia	ICD-9-CM Diagnosis Code	518.3
Nervous System		
Multiple sclerosis	ICD-9-CM Diagnosis Code	340

TABLE A.1 (*continued*)

Condition	Type of Code	Code
Transplantation		
Organ transplants:		
Kidney (renal)	ICD-9-CM Diagnosis Code	V42.0
	CPT-4 Procedure Code	50360, 50365
	ICD-9-CM Procedure Code	55.69
(reimplant)	CPT-4 Procedure Code	50380
(anaesthesia)	CPT-4 Procedure Code	00868
	DRG	302
Heart	ICD-9-CM Diagnosis Code	V42.1
	CPT-4 Procedure Code	33945
	ICD-9-CM Procedure Code	37.5
(anaesthesia)	CPT-4 Procedure Code	00580
	DRG	103
Lung	ICD-9-CM Diagnosis Code	V42.6
	CPT-4 Procedure Code	33935
	ICD-9-CM Procedure Code	33.5, 33.6
Liver	ICD-9-CM Diagnosis Code	V42.7
	CPT-4 Procedure Code	47135
	ICD-9-CM Procedure Code	50.5
(anaesthesia)	CPT-4 Procedure Code	00796
	DRG	480
Bone marrow	CPT-4 Procedure Code	38240, 38241
	ICD-9-CM Procedure Code	41.0
	DRG	481
Unspecified organ	ICD-9-CM Diagnosis Code	V42.9
Complication of transplanted organ	ICD-9-CM Diagnosis Code	996.8x

TABLE A.1 (*continued*)

Condition	Type of Code	Code
Renal Failure[a]	ICD-9-CM Diagnosis Code	585, 586
and		and
evidence of dialysis	ICD-9-CM Diagnosis Code	V56.x
	CPT-4 Procedure Code	90935, 90937, 90945, 90947, 90989,
	ICD-9-CM Procedure Code	90993, 90995, 90997, 90998, 90999
		39.95, 54.98
Neoplasms		
Leukemias		204.xx-208.xx
Pancreas		157.x
Multiple myeloma and immunoproliferative neoplasms		203.x

[a]Because AIDS can cause renal failure, cases with these codes were flagged for exclusion of 279.xx codes as evidence of HIV infection only if there was no evidence in the case record of conditions highly specific to AIDS: Karposi's sarcoma (176.x), toxoplasmosis (130.0, 130.7, 130.8, 130.9), disseminated atypical mycobacterial infection (031.8, 031.9), or cytomegalovirus disease (078.5, 484.1).

TABLE A.2

ICD-9-CM CODES FOR AIDS-INDICATOR DIAGNOSIS: ADOLESCENTS AND ADULTS

Conditions Included in the CDC Definition and Used in Our Algorithm as AIDS-defining for Adolescents and Adults	Single Codes		Combination Codes[a]	
	Diagnoses	Codes	Diagnoses	Codes
Candidiasis of bronchi, trachea, or lungs	Candidiasis of lung; disseminated candidiasis; candidal endocarditis; candidal meningitis; candidal enteritis[a]; candidiasis of other site[b]	112.4; 112.5; 112.81; 112.83; 112.85[c]; 112.89		
Candidiasis, esophageal	Candidal esophagitis	112.84[d]	1 claim for candidiasis of mouth + 1 claim for esophagitis[d]	112.0 + 530.1
Cervical cancer, invasive	Cervical neoplasm	180.x		
Coccidioidomycosis, disseminated or extrapulmonary	Coccidioidomycosis (various sites)	114.x		
Cryptococcosis, extrapulmonary	Cryptococcosis; cryptococcal meningitis	117.5; 321.0		
Cryptosporidiosis, chronic intestinal	Coccidiosis	007.2		
Cytomegalovirus disease (other than liver, spleen, or nodes)	Cytomegalic inclusion disease; pneumonia in cytomegalic disease	078.5; 484.1		
Cytomegalovirus retinitis (with loss of vision)	See "Cytomegalovirus disease" (above)[e]		Cytomegalic inclusion disease + Chorioretinitis and retinochoroiditis claims (see Table A.3 for specific diagnoses)	078.5 + 363.0x; 363.1x; 363.20; 363.21
Encephalopathy, HIV-related[f]			Two claims for dementia (see Table A.3 for specific diagnoses)	290.1; 310.9; 323.8; 323.9; 331.9; 341.8; 348.3; 348.8

TABLE A.2 *(continued)*

Conditions Included in the CDC Definition and Used in Our Algorithm as AIDS-defining for Adolescents and Adults	Single Codes		Combination Codes[as]	
	Diagnoses	Codes	Diagnoses	Codes
Herpes simplex: organ involvement	Herpetic meningoencephalitis; herpetic septicemia; visceral herpes simplex; herpes simplex meningitis; herpes simplex with other specified complications; herpes simplex with unspecified complication	054.3; 054.5; 054.71-054.72; 054.79; 054.8		
Herpex simplex: chronic ulcers			Genital herpes, herpetic gingivostomatitis, Herpes simplex with ophthalmic complications, herpes simplex otitis externa	054.1-054.2, 054.4, 054.73
Histoplasmosis, disseminated or extrapulmonary	Disseminated histoplasmosis (histoplasmosis with meningitis, retinitis, pericarditis, endocarditis, or other manifestation)	115.x1; 115.x2; 115.x3; 115.x4; 115.x9		
Isosporiasis, chronic intestinal	See "Cryptosporidiosis, chronic intestinal" (above)			
Isosporiasis, chronic intestinal	See "Cryptosporidosis, chronic intestinal" (above)			
Kaposi's sarcoma	Kaposi's sarcoma Other malignant neoplasms of the skin	176.x 173.x[a]		
Lymphoma, Burkitt's (or equivalent term)	Burkitt's tumor or lymphoma (all sites)	200.20-200.28		
Lymphoma, immunoblastic (or equivalent term)	AIDS-related lymphomas: reticulosarcoma (all sites); other named variants. These codes are meant to exclude: 200.10-200.18 (lymphosarcoma, all sites)	200.00-200.08, 200.80-200.88		
	Other lymphomas (inpatient claims only)[h]	202.8x	Other lymphomas (outpatient claims)[h]	202.8x

TABLE A.2 *(continued)*

Conditions Included in the CDC Definition and Used in Our Algorithm as AIDS-defining for Adolescents and Adults	Single Codes		Combination Codes[m]	
	Diagnoses	Codes	Diagnoses	Codes
Lymphoma, primary, of brain	Reticulosarcoma, lymph nodes of head, face, and neck; lymphosarcoma, other named variants, lymph nodes of head, face, and neck; lymphoma, lymph nodes of head, face, and neck[l]	200.01; 200.81; 202.81		
Mycobacterium avium complex or *M. kansasii*, disseminated or extrapulmonary	Disseminated atypical mycobacterial infection (MAC disease)	031.8, 031.9		
Mycobacterium tuberculosis				
Pulmonary	Tuberculous pleurisy in primary progressive tuberculosis; other primary progressive tuberculosis; pulmonary tuberculosis; tuberculous pleurisy; tuberculosis of intrathoracic lymph nodes; isolated tracheal or bronchial tuberculosis; tuberculous laryngitis	010.1; 010.8; 011.x; 012.0; 012.1; 012.2; 012.3		
Extrapulmonary	Tuberculosis of meninges and central nervous system; tuberculosis of intestines, peritoneum, and mesenteric glands; tuberculosis of bones and joints; tuberculosis of genitourinary system; tuberculosis of other organs; miliary tuberculosis	013.x-018.x		
Pneumocystis carinii pneumonia (PCP)	Pneumonia due to *Pneumocystis carinii*	136.3		

TABLE A.2 *(continued)*

Conditions Included in the CDC Definition and Used in Our Algorithm as AIDS-defining for Adolescents and Adults	Single Codes		Combination Codes[a]	
	Diagnoses	Codes	Diagnoses	Codes
Pneumonia, recurrent			Two claims for any type of pneumonia (see Table III.3a for specific diagnoses) (Note: for patients ages 13-59)	003.22; 480.x; 481.x - 483.x; 484.6- 484.8; 485.x - 486.x; 511.0 - 511.1; 513.x
			1 claim for bacterial or fungal pneumonia (pneumococcal pneumonia, other bacterial pneumonia, pneumonia in aspergillosis, or pneumonia in other systemic mycoses) + 1 claim for any type of pneumonia[j] (Note: for patients age over age > 59)	481.x - 482.x; 484.6; 484.7 + See above
Progressive multifocal leukoencephalopathy (PML)	Progressive multifocal leukoencephalopathy (PML)	046.3		
Salmonella septicemia, recurrent	*Salmonella* septicemia[k]	003.1		
Toxoplasmosis of brain	Meningoencephalitis due to toxoplasmosis, toxoplasmosis of other specified sites; multisystemic disseminated toxoplasmosis, unspecified toxoplasmosis	130.0; 130.7; 130.8, 130.9[l]		

TABLE A.2 *(continued)*

Conditions Included in the CDC Definition and Used in Our Algorithm as AIDS-defining for Adolescents and Adults	Single Codes		Combination Codes[aa]	
	Diagnoses	Codes	Diagnoses	Codes
Wasting syndrome due to HIV	Wasting syndrome, severe weight loss. Nutritional marasmus, other severe protein-calorie malnutrition, malnutrition of moderate degree, cachexia	261; 262; 263.0; 799.4	2 claims for wasting syndrome, less severe weight loss (see Table A.3 for specific diagnoses)	263.1; 263.8; 263.9; 783.2[ab]
Conditions Often Associated with Low CD4 Count				
Atypical *mycobacterium* pulmonary infection	Pulmonary diseases due to other mycobacteria	031.0		
Septicemia	Bacterial septicemia: listeriosis; streptococcal septicemia; staphylococcal septicemia; septicemia due to anaerobes; septicemia due to other gram-negative organisms (unspecified, hemophilus influenzae, escherichia coli, pseudomonas, serratia, other); other specified septicemias; unspecified septicemia	027.0, 038.0-038.3, 038.4-038.49, 038.8, 038.9		
Intestinal infectious diseases			2 claims for other intestinal infectious diseases (see Table III.A.3 for specific diagnoses)	003.0; 004.x; 008.0-008.5

TABLE A.2 *(continued)*

Conditions Included in the CDC Definition and Used in Our Algorithm as AIDS-defining for Adolescents and Adults	Single Codes		Combination Codes[a]	
	Diagnoses	Codes	Diagnoses	Codes
Conditions Often Associated with Low CD-4 Count				
Meningitis	Salmonella meningitis, bacterial meningitis, unspecified meningitis	003.21; 320.x; 322.9		
Renal diseases			Nephritis, nephrotic syndrome, renal failure	580.x-583.x; 584.x-586.x
Other retinopathy			Other background retinopathy, other proliferative retinopathy	362.1x-362.2x
Intracranial abscess	Intracranial abscess	324.0		
Microsporidiosis	Microsporidiosis	136.8		
Molluscum contagiosum			Molluscum contagiosum	078.0

NOTE: We required combinations of diagnosis codes to establish the presence of certain conditions. At least two of the diagnoses must be separated by a specific period of time and/or occur within a specific time span. See Table A.3 for these time interval requirements.

[a]The code for candidal enteritis was not available in 1992.

[b]The CDC definition is effectively looking for disseminated candidiases; therefore, we have included visceral candidiasis and other conditions that have a worse prognosis than those specified by the CDC.

[c]This code did not exist in 1992.

[d]Because the code for candidal esophagitis was not available in 1992, physicians may have coded this condition with a combination of candidiasis of mouth and esophagitis. Code 112.89 was also commonly used for esophageal candidiasis.

[e]There is no specific ICD-9-CM code for this condition.

[f]There is no specific ICD-9-CM code for this condition. Recently, code 043.1 (HIV infection causing specified disease of the central nervous system) has probably been the most commonly used code for HIV-related encepalopathy. Although this is the case, we do not include the code here because we chose to use code 043.1 as evidence of HIV infection (see Table 3). It is also common to find code 348.3 (encephalopathy, unspecified) on claims for individuals with HIV infection.

TABLE A.2 *(continued)*

[g] This code is for other malignant neoplasm of the skin and was used to report Kaposi's sarcoma (KS) before KS had its own code (176.x). The specific KS code was available during the study period. In populations without known HIV diagnosis, we consider only 176.x an AIDS-defining diagnosis.

[h] Previous studies have found that this code frequently appears in inpatient claims for cases in which there is strong evidence of AIDS. When this condition is managed in the outpatient setting, we require that the code appear on more than one claim.

[i] There is no ICD-9-CM code for lymphoma of the brain, so codes for lymphoma of the head, face, and neck were used.

[j] Because pneumonia is fairly common among adults, particularly those over age 60, we require that at least one episode be identified as of bacterial origin for this population.

[k] Although the CDC definition requires recurrent Salmonella septicemia, we have used a single occurrence of Salmonella septicemia as an AIDS-defining diagnosis because previous work has shown similar survival curves for the very small subset of the population with two claims with septicemia as for the much larger population with one such claim.

[l] These codes are considered AIDS-defining only if the individual has not had any claims with a code for "other congenital infections - toxoplasmosis" (771.2) before this claim nor within six months after this claim.

[m] This set of codes demonstrates less profound weight loss. Accordingly, we require at least two occurrences of these codes as evidence of wasting syndrome. Although it is technically required that wasting syndrome be accompanied by persistent fever and/or diarrhea, it is unlikely that this combination of conditions would all be recorded on claims data. Therefore, we only require evidence of wasting.

TABLE A.3

ICD-9-CM CODES FOR AIDS-INDICATOR DIAGNOSIS: ADOLESCENTS AND ADULTS
Combination Codes

Age of Patient[a]	Claim Codes Required	Description	Period of Time That Must Separate Claims[b]	Time Span During Which Claims Must Occur
≥ 13 years	290.1; 310.9; 323.8; 323.9; 331.9; 341.8; 348.3; 348.8	2 claims for dementia:[c] presenile dementia, unspecified nonpsychotic mental disorder following organic brain damage, other causes of encephalitis, unspecified cause of encephalitis, unspecified cerebral degeneration, other demyelinating diseases of the central nervous system, unspecified encephalopathy, other conditions of brain	1 month	6 months
≥ 13 years	263.1; 263.8; 263.9, 783.2[d]	2 claims for wasting syndrome/less severe weight loss: malnutrition of mild degree, other and unspecific protein-calorie malnutrition, abnormal weight loss	1 month	3 months
≥ 13 years	112.0 530.1	1 claim for candidiasis of mouth + 1 claim for esophagitis[e]	NA	1 month
13-59 years	003.22; 480.x; 481.x-483.x; 484.6-484.8; 485.x-486.x; 511.0-511.1; 513.x	2 claims for pneumonia, any type: Salmonella pneumonia; viral pneumonia; pneumococcal pneumonia; other bacterial pneumonia; pneumonia due to other specified organism; pneumonia in aspergillosis; pneumonia in other systemic mycoses; pneumonia in other infectious diseases classified elsewhere; bronchopneumonia organism unspecified; pneumonia organism unspecified; pleurisy without mention of effusion or current tuberculosis; pleurisy with effusion, with mention of a bacterial cause other than tuberculosis: abscess of lung and mediastinum	2 months	1 year
≥ 60 years	481.x-482.x; 484.6; 484.7 + See above	1 claim for bacterial or fungal pneumonia (pneumococcal pneumonia, other bacterial pneumonia, pneumonia in aspergillosis, or pneumonia in other systemic mycoses) + 1 claim for any type of pneumonia[f]	2 months	1 year
≥ 13	078.5 + 363.0x; 363.1x; 363.20; 363.21	Cytomegalic inclusion disease + Focal chorioretinitis and focal retinochoroiditis; disseminated chorioretinitis and disseminated retinochoroiditis; other and unspecified forms of chorioretinitis and retinochoroiditis: chorioretinitis, unspecified; pars planitis	1 month	3 months

TABLE A.3 *(continued)*

Age of Patient[a]	Claim Codes Required	Description	Period of Time That Must Separate Claims[b]	Time Span During Which Claims Must Occur
≥ 13	054.1-054.2; 054.4; 054.73	Genital herpes, herpetic gingivostomatitis, herpes simplex with opthalmic complications, Herpes simplex, otitis externa	1 month	3 months
≥ 13	202.8x	Other lymphomas (outpatient claims)[g]	1 month	6 months
≥ 13	003.0; 004.x; 008.0-008.5	Salmonella gastroenteritis, shigellosis, intestinal infections due to: e. coli, arizona group of paracolon facilli, aerobacter aerogenes, proteus (mirabilis) (morganii), other specied bacteria, bacterial enteritis unspecified	1 month	3 months
≥ 13	580.x-583.x; 584.x-586.x	Acute glomerulonephritis, nephrotic syndrome, chronic glomerulonephritis, nephritis and nephropathy, not specified as acute or chronic, acute renal failure, chronic renal failure, renal failure unspecified	1 month	6 months
≥ 13	362.1x-362.2x	Other background retinopathy; other proliferative retinopathy	1 month	6 months
≥ 13	078.0	Molluscum contagiosum	1 month	3 months

[a]The age of the patient is his or her age in the month during which the more recent of the two selected claims occurred.

[b]Because a single encounter can generate multiple claims, we considered multiple claims to be evidence of multiple occurrences of a condition only if the claims were separated in time.

[c]There is no specific ICD-9-CM code for this condition. Recently, code 043.1 (HIV infection causing specified disease of the central nervous system) has probably been the most commonly used code for HIV-related encepalopathy. However, we do not include the code here because we chose to use code 043.1 as evidence of HIV infection (see Table 3). It is also common to find code 348.3 (encephalopathy, unspecified) on claims for individuals with HIV infection.

[d]This set of codes demonstrates less profound weight loss. Accordingly, we require at least two occurrences of these codes as evidence of wasting syndrome. Although it is technically required that wasting syndrome be accompanied by persistent fever and/or diarrhea, it is unlikely that this combination of conditions would all be recorded on claims data. Therefore, we require only evidence of wasting.

[e]Because the code for candidal esophagitis was not available in 1992, physicians may have coded this condition with a combination of candidiasis of mouth and esophagitis.

[f]Because pneumonia is more common among older individuals, we require that at least one episode be identified as of bacterial origin in this population for *all* adults over age 60.

[g]Previous studies have found that this code frequently appears in inpatient claims for cases in which there is strong evidence of AIDS. When this condition is managed in the outpatient setting, we require the code to appear on more than one claim.

TABLE A.4

ICD-9-CM CODES FOR AIDS-INDICATOR DIAGNOSIS: CHILDREN (UNDER AGE 13)

Conditions Included in the CDC Definition and Used in Our Algorithm as AIDS-defining for Children Under Age 13	Single Codes		Combination Codes	
	Diagnoses	Codes	Diagnoses	Codes
Candidiasis of bronchi, trachea, or lungs	Candidiasis of lung; disseminated candidiasis; candidal endocarditis; candidal meningitis; candidal enteritis;[a] candidiasis of other site[b]	112.4; 112.5; 112.81; 112.83; 112.85[c]; 112.89		
Candidiasis, esophageal	Candidal esophagitis	112.84[d]	1 claim for candidiasis of mouth + 1 claim for esophagitis[d]	112.0 530.1
Coccidioidomycosis, disseminated (at site other than or in addition to lungs or cervical or hilar lymph nodes)	Coccidioidomycosis (various sites)	114.x		
Cryptococcosis, extrapulmonary	Cryptococcosis, cryptococcal meningitis	117.5; 321.0		
Cryptosporidiosis or isosporiasis with diarrhea persisting > 1 month	Coccidiosis	007.2		
Cytomegalovirus disease (other than liver, spleen, or nodes)[f]	Cytomegalic inclusion disease; pneumonia in cytomegalic disease	078.5; 484.1		
Cytomegalovirus retinitis (with loss of vision)	See "Cytomegalovirus disease" (above)[e]		Cytomegalic inclusion disease + Chorioretinitis and retinochoroiditis claims (see Table A.5 for specific diagnoses)	078.5 + 363.0x; 363.1x; 363.20; 363.21
Encephalopathy, HIV-related[f]			2 claims for dementia (see Table A.5 for specific diagnoses)	290.1; 310.9; 323.8; 323.9; 331.9; 348.3; 341.8; 348.8

TABLE A 4 *(continued)*

Conditions Included in the CDC Definition and Used in Our Algorithm as AIDS-defining for Children Under Age 13	Single Codes		Combination Codes	
	Diagnoses	Codes	Diagnoses	Codes
Herpes simplex: organ involvement	Herpetic meningoencephalitis; herpetic septicemia; visceral herpes simplex; herpes simplex meningitis; herpes simplex with other specified complications; herpes simplex with unspecified complications	054.3; 054.5; 054.71-054.72; 054.79; 054.8		
Herpex simplex: chronic ulcers			Genital herpes, herpetic gingivostomatitis, Herpes simplex with ophthalmic complications, herpes simplex otitis externa	054.1-054.2, 054.4, 054.73
Histoplasmosis, disseminated or extrapulmonary	Disseminated histoplasmosis (histoplasmosis with meningitis, retinitis, pericarditis, endocarditis, or other manifestation)	115.x1; 115.x2; 115.x3; 115.x4; 115.x9		
Kaposi's sarcoma	Kaposi's sarcoma Other malignant neoplasms of the skin	176.x 173.x[g]		
Lymphoid interstitial pneumonia (LIP)	LIP	516.8		
Lymphoma, Burkitt's (or equivalent term)	Burkitt's tumor or lymphoma (all sites)	200.20-200.28		
Lymphoma, immunoblastic or large cell lymphoma of B-cell or unknown immunologic phenotype	AIDS-related lymphomas: reticulosarcoma (all sites); other named variants. These codes are meant to exclude: 200.10-200.18 (lymphosarcoma, all sites)	200.00-200.08, 200.80-200.88		
	Other lymphomas (inpatient claims)[h]	202.8x	Other lymphomas (outpatient claims)[h]	202.8x

TABLE A.4 *(continued)*

Conditions Included in the CDC Definition and Used in Our Algorithm as AIDS-defining for Children Under Age 13	Single Codes		Combination Codes	
	Diagnoses	Codes	Diagnoses	Codes
Lymphoma, primary, of brain	Reticulosarcoma, lymph nodes of head, face, and neck; lymphosarcoma, other named variants, lymph nodes of head, face, and neck; lymphoma, lymph nodes of head, face, and neck[i]	200.01; 200.81; 202.81		
Mycobacterium avium complex or *M. kansasii*, disseminated or extrapulmonary	Disseminated atypical mycobacterial infection (MAC disease)	031.9; 031.8		
Mycobacterium tuberculosis, disseminated or extrapulmonary	Tuberculosis of meninges and central nervous system; intestines, peritoneum, and mesenteric glands; bones and joints; genitourinary system; other organs; miliary tuberculosis	013.x-018.x		
Pneumocystis carinii pneumonia (PCP)	*Pneumocystis carinii* pneumonia (PCP)	136.3		
Progressive multifocal leukoencephalopathy (PML)	Progressive multifocal leukoencephalopathy (PML)	046.3		
Salmonella septicemia, recurrent			2 claims for *Salmonella* septicemia	003.1
Toxoplasmosis of brain	Meningoencephalitis due to toxoplasmosis, toxoplasmosis of other specified areas; multisystemic disseminated toxoplasmosis, unspecified toxoplasmosis	130.0; 130.7; 130.8; 130.9[i]		

TABLE A.4 *(continued)*

Conditions Included in the CDC Definition and Used in Our Algorithm as AIDS-defining for Children Under Age 13	Single Codes		Combination Codes	
	Diagnoses	Codes	Diagnoses	Codes
Wasting syndrome due to HIV	Wasting syndrome, severe weight loss. Nutritional marasmus, other severe protein-calorie malnutrition, malnutrition of moderate degree; cachexia	261; 262; 263.0; 799.4	2 claims for wasting syndrome, less severe weight loss or lack of expected normal physiological development (see Table A.5 for specific diagnoses)[a]	263.1; 263.2; 263.8; 263.9; 783.2; 783.4
Serious bacterial infections, multiple or recurrent of the following types: septicemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity			2 claims for serious bacterial infections (see Table A.5 for specific diagnoses)	See Table A.5 for specific codes
			1 claim for infections not known to be of bacterial etiology or 1 claim for unspecified pneumonia + 1 claim for any serious bacterial infection (see Table A.5 for specific diagnoses)	038.9; 320.9; 322.9; 711.9x; 421.9x; 429.0; 485; 486 See Table A.5 for specific codes

SOURCE: We required combinations of diagnosis codes to establish the presence of certain conditions. At least two of the diagnoses must be separated by a specific period of time and/or occur within a specific time span. See Table A.5 for these time interval requirements.

[a]The code for candidal enteritis was not available in 1992.

[b]The CDC definition is effectively looking for disseminated candidiases; therefore, we have included visceral candidiasis and other conditions that have a worse prognosis than those specified by CDC.

[c]This code did not exist in 1992.

[d]Because the code for candidal esophagitis was not available in 1992, physicians may have coded this condition with a combination of candidiasis of mouth and esophagitis. Code 112.89 was also commonly used for esophageal candidiasis.

[e]There is no specific ICD-9-CM code for this condition.

[f]There is no specific ICD-9-CM code for this condition. Recently, code 043.1 (HIV infection causing specified disease of the central nervous system) has probably been the most commonly used code for HIV-related encepalopathy. Although this is the case, we do not include the code here because we chose to use code 043.1 as evidence of HIV infection (see Table III-5). It is also common to find code 348.3 (encephalopathy, unspecified) on claims for individuals with HIV infection.

TABLE A.4 *(continued)*

[a] This code is for other malignant neoplasm of the skin, and was used to report Kaposi's sarcoma (KS) before KS had its own code (176.x). The specific KS code was available during the study period. In populations without known HIV diagnosis, we consider only 176.x an AIDS-defining diagnosis.

[b] Previous studies have found that this code frequently appears in inpatient claims for cases in which there is strong evidence of AIDS. When this condition is managed in the outpatient setting, we require that the code appear on more than one claim.

[i] There is no ICD-9-CM code for lymphoma of the brain, so codes for lymphoma of the head, face, and neck were used here.

[l] These codes are considered AIDS-defining only if the individual has not had any claims with a code for "other congenital infections - toxaplasmosis" (771.2) before this claim or within six months after this claim.

[n] This set of codes demonstrates less profound weight loss. Accordingly, we require at least two occurrences of these codes as evidence of wasting syndrome. Note the addition, for children, of codes denoting lack of expected normal physiological development. Although it is technically required that wasting syndrome be accompanied by persistent fever and/or diarrhea, it is unlikely that this combination of conditions would all be recorded on claims data. Accordingly, we require only evidence of wasting.

TABLE A.5

ICD-9-CM CODES FOR AIDS-INDICATOR DIAGNOSIS: CHILDREN (UNDER AGE 13)
Combination Codes

Age of Patient[a]	Claim Codes Required	Description	Period of Time That Must Separate Claims[b]	Time Span During That Claims Must Occur
≤13 years		2 claims for serious bacterial infections of the following types:	2 months	2 years
	003.1	*Salmonella* septicemia		
	027.0; 036.2; 038.0-038.3; 038.4-038.49; 038.8	Bacterial septicemia: listeriosis; meningococcemia; streptococcal septicemia; staphylococcal septicemia; septicemia due to anaerobes; septicemia due to other gram-negative organisms (hemophilus influenzae, escherichia coli, pseudomonas, serratia, other); other specified septicemias		
	003.22; 481.x; 482.x; 511.0-511.1; 513.x	Bacterial pneumonia or bacterial pleurisy, abscess of lung: Salmonella pneumonia; pneumococcal pneumonia; other bacterial pneumonia; pleurisy without mention of effusion or current tuberculosis; pleurisy with effusion, with mention of a bacterial cause other than tuberculosis; abscess of lung and mediastinum		
	003.21; 006.5; 036.0-036.1; 098.82; 100.81; 320.0-320.3; 320.7; 320.8x; 323.1; 324.0; 324.1; 324.9	Meningitis: Salmonella meningitis; amebic brain abscess; meningococcal meningitis; meningococcal encephalitis; gonococcal meningitis; leptospiral meningitis; hemophilus meningitis; pneumococcal meningitis; streptococcal meningitis; staphylococcal meningitis; meningitis in other bacterial diseases classified elsewhere; meningitis due to other specified bacteria; encephalitis in rickettsial diseases classified elsewhere; intracranial abscess; intraspinal abscess; intracranial and intraspinal abscess of unspecified site.		
	003.24; 376.01-376.03; 383.xx; 422.92; 510.x, 513.0-513.1; 526.4; 527.3; 530.19[c]; 540.1; 567.2; 569.5; 572.0; 575.0; 577.0; 590.2; 711.0x; 711.8x; 730.xx	Visceral abscesses: Salmonella osteomyelitis; orbital cellulitis; orbital periostitis; orbital osteomyelitis; mastoiditis and related conditions; septic myocarditis; empyema; abscess of lung; abscess of mediastinum; inflammatory conditions of the jaws; abscess of the salivary glands; other esophagitis; acute appendicitis with peritoneal abscess; other suppurative peritonitis; abscess of intestine; abscess of liver; acute cholecystitis; acute pancreatitis; renal and perinephric abscess; pyogenic arthritis; arthropathy associated with other infectious and parasitic diseases; osteomyelitis, periostitis, and other infections involving bone		

TABLE A.5 *(continued)*

Age of Patient[a]	Claim Codes Required	Description	Period of Time That Must Separate Claims[b]	Time Span During That Claims Must Occur
	032.82; 036.42-036.43; 093.2x; 098.83-098.85; 391.x; 421.0-421.1; 422.0; 422.90; 422.92; 429.89	Myoendocarditis: diphtheritic myocarditis; meningococcal endocarditis; meningococcal myocarditis; syphilitic endocarditis; gonococcal pericarditis, endocarditis, and other heart disease; rheumatic fever with heart involvement; acute and subacute endocarditis; acute myocarditis in diseases classified elsewhere; septic myocarditis; other ill-defined heart diseases		
	038.9; 320.9; 322.9; 711.9x; 421.9x; 429.0; 485; 486	Infections not known to be of bacterial etiology: unspecified septicemia; meningitis due to unspecified bacteria; meningitis, unspecified; unspecified infective arthritis; acute myocarditis unspecified; unspecified myocarditis; unspecified pneumonia + 1 claim for any serious bacterial infection of the types listed above	2 months	2 years
≤13 years	290.1; 310.9; 323.8; 323.9; 331.9; 341.8; 348.3; 348.8	2 claims for dementia;[d] presenile dementia, unspecified nonpsychotic mental disorder following organic brain damage, other causes of encephalitis, unspecified cause of encephalitis, unspecified cerebral degeneration, other demyelinating diseases of the central nervous system, unspecified encephalopathy; other conditions of the brain	1 month	6 months
≤13 years	263.1; 263.2; 263.8; 263.9; 783.2; 783.4	2 claims for wasting syndrome:[e] less severe weight loss. (Malnutrition of mild degree, arrested development following protein-calorie malnutrition, other and unspecific protein-calorie malnutrition, abnormal weight loss, abnormal loss of weight, lack of expected normal physiological development.	1 month	3 months
≤13 years	112.0 530.1	1 claim for candidiasis of mouth + 1 claim for esophagitis[f]	NA	1 month

[a]The age of the patient is his or her age in the month during which the more recent of the two selected claims occurred.

[b]Because a single encounter can generate multiple claims, we considered multiple claims to be evidence of multiple occurrences of a condition only if the claims were separated in time.

[c]This code did not exist in 1992.

[d]There is no specific ICD-9-CM code for this condition. Recently, code 043.1 (HIV infection causing specified disease of the central nervous system) has probably been the most commonly used code for HIV-related encephalopathy. However, we do not include the code here because we chose to use code 043.1 as evidence of HIV infection (see Table 3). It is also common to find code 348.3 (encephalopathy, unspecified) on claims for individuals with HIV infection.

TABLE A.5 *(continued)*

[e]This set of codes demonstrates less profound weight loss. Accordingly, we require at least two occurrences of these codes as evidence of wasting syndrome. Note the addition, for children, of codes denoting lack of expected normal physiological development. Also note that, although it is technically required that wasting syndrome be accompanied by persistent fever and/or diarrhea, it is unlikely that this combination of conditions would all be recorded on claims data. Therefore, we require only evidence of wasting.

[f]Because the code for candidal esophagitis was not available in 1992, physicians may have coded this condition with a combination of candidiasis of mouth and esophagitis.

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